



THE UNIVERSITY *of* EDINBURGH

This thesis has been submitted in fulfilment of the requirements for a postgraduate degree (e.g. PhD, MPhil, DClinPsychol) at the University of Edinburgh. Please note the following terms and conditions of use:

- This work is protected by copyright and other intellectual property rights, which are retained by the thesis author, unless otherwise stated.
- A copy can be downloaded for personal non-commercial research or study, without prior permission or charge.
- This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the author.
- The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author.
- When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given.

Emotion Regulation and Positive Growth in Spousal Dementia Carers

Roisin Ash



Doctorate in Clinical Psychology

The University of Edinburgh

2013

Table of Contents

SECTION	PAGE
Declaration	iv
Acknowledgements	v
Chapter contents and format summary	vi
List Of Tables	vii
List Of Figures	viii
List Of Abbreviations	ix
Word Counts	x
Abstract	xi

Chapter 1: Systematic Review: What happens to spousal dementia carer emotional well-being before and after care home placement?

1.1	Abstract	1
1.2	Introduction	2
1.3	Aims	8
1.4	Methods	9
1.5	Results	12
1.6	Limitations of studies included in the review	43
1.7	Discussion	
1.7.1	Summary of results	44
1.7.2	Key findings: review question 1	45
1.7.3	Key findings: review question 2	46
1.7.3.1	Carers who continued to live with their spouse at home	46
1.7.3.2	Carers who experience transition of spouse to care home	48
1.7.4	Inconsistent results and methodological issues	51
1.7.5	Review limitations	52
1.7.6	Clinical implications	53
1.7.7	Research recommendations	54
1.8	Conclusions	55
1.9	References	56

Chapter 2: The Research Context

2.1	Introduction	73
2.2	Care transition	74
2.3	The evidence base	
2.3.1	The imbalance in carer research	74
2.3.2	Post traumatic growth	75
2.3.3	Emotion regulation	76
2.4	Summary	77
2.5	Thesis focus	77

Chapter 3: Journal article: Emotion Regulation and Positive Growth in Spousal

Dementia Carers

3.1	Abstract	81
3.2	Introduction	83
3.3	Methods	
3.3.1	Design	90
3.3.2	Participants	91
3.3.3	Basic Emotions Scale (BES)	91
3.3.4	Regulation of Emotions Questionnaire (REQ)	92
3.3.5	Post Traumatic Growth Inventory (PTGI)	93
3.3.6	Data Analysis	94
3.4	Results	
3.4.1	Descriptive Statistics	95
3.4.2	Principal Components Analysis	96
3.4.3	Data Reduction and Scale Trimming	97
3.4.4	Care Transition, Gender, Emotion Regulation and Positive Growth (PTGI)	103
3.4.5	Relationship between Positive Growth and Emotion Regulation	107
3.4.6	Relative frequency of Emotions Experienced and Strategies used	110

3.5	Discussion	
3.5.1	Summary of key findings	112
3.5.2	Hypothesis 1	112
3.5.3	Hypothesis 2	116
3.5.4	Hypothesis 3	117
3.5.5	Using the PTGI, BES and REQ with Spousal Dementia Carers	118
3.5.6	Limitations of the study	120
3.5.6	Clinical implications	122
3.5.7	Research recommendations	123
3.6	Conclusions	124
3.7	References	125
3.8	Appendices	140
	Thesis Portfolio References	143
	Appendices	
	Appendix 1 International Psychogeriatrics Author Guidelines	174
	Appendix 2 Clinical Psychology and Psychotherapy Author Guidelines	183
	Appendix 3 Distribution of scores the BES, REQ and PTGI	190
	Appendix 4 Z Score Frequencies for the BES, REQ and PTGI	193
	Appendix 5 IRAS Ethical Approval	196
	Appendix 6 Survey cover letter	200
	Appendix 7 Participant Information Sheet	201
	Appendix 8 SDCRN Approval	203
	Appendix 9 The Basic Emotions Scale	204
	Appendix 10 Regulation of Emotions Questionnaire	205
	Appendix 11 Post Traumatic Growth Inventory	207

Declaration

I declare that this thesis and the research on which it is based are my own work. I confirm that this work has not been submitted for any other degree or professional qualification.

Roisin Ash

October 2013

Acknowledgements

I am privileged to have been able to work with and learn from a range of clients and their families who live with dementia, all of whom inspire my continued questioning and learning and my motivation to share that learning compassionately.

I would like to thank each carer for taking part in this research – this thesis exists through your experiences.

My work has also been shaped by personable input from Ken Laidlaw, my academic supervisor, upon whom I was able to rely for inspiration and support - my sincere thanks. I would also like to thank Ray French for expertise and humour in supporting my IRAS (research passion killer) application, Rowena Stewart, Liaison Librarian, for sharing expertise on database searching, Hasnain Sheikh, sub postmaster at Warriston Post Office, for gracefully processing hundreds of survey packs without batting an eyelid, and my fantastic BodyBalance class who kept me in touch with things that feel important when far away from home. A special mention has to go to other trainees for shared support and much needed laughter on ‘come dine with me’ evenings which enabled us to survive the punitive ‘parenting’ we endured on placement.

I am eternally grateful for Malcolm’s compassion, guidance and good humour and for the love and experiences I share with my friends, family and partner. My heart-felt thanks are with Fiona who had faith that clinical psychology is a career for me, long before I did. I am glad that I listened to you before it was too late.

Content and Format

Chapter 1: Systematic Review is written in adherence of guidelines specified by International Psychogeriatrics. References cited within this article are listed at the end of this chapter. Appendix 1, pp. 174 – 182, displays the author guidelines for this journal.

Chapters 2: The Research Context is written in adherence of guidelines specified by the British Psychological Society (2004). A reference list containing the articles cited in this chapter combined with references in all other chapters is provided at the end of the thesis.

Chapter 3: Journal Article: Emotion Regulation and Positive Growth in Spousal Dementia Carers is written in adherence of guidelines specified by Clinical Psychology & Psychotherapy. References cited within this article are listed at the end of this chapter. Appendix 2, pp. 183 – 189, displays the author guidelines for this journal.

List Of Tables

Systematic Review

Table 1: Quality criteria: definitions for critical appraisal of review articles	11
Table 2: Methodological quality indicators of longitudinal studies included for review	15
Table 3: Summary of methodology and quality ratings for each included study	19
Table 4: Carer outcome measures: emotional well-being	29
Table 5: Care recipient outcomes measures: dementia severity	30
Table 6: Summary of analysis, results and conclusions of studies included for review	36

Journal Article

Table 1: Descriptive statistics for participants by care transition	96
Table 2: Mean, standard deviation and internal consistency of BES Factors	98
Table 3: Data reduction of BES responses	99
Table 4: Mean, standard deviation and internal consistency of REQ Factors	100
Table 5: Data reduction of REQ responses	100
Table 6: Mean, standard deviation and internal consistency of PTGI Factors	102
Table 7: Data reduction of REQ responses	102
Table 8: Mean BES, REQ and PTGI scores by care transition	104
Table 9: Mean BES and REQ scores by gender	105
Table 10: Partial correlations between REQ, BES and PTGI scores	107
Table 11: Linear model of predictors of positive growth in dementia carers	109
Table 12: Within group t-tests for BES, REQ and PTGI scores	111
Table 13: Correlations between BES Factors: Factor correlation matrix	140
Table 14: Correlations between REQ Factors: Factor correlation matrix	141
Table 15: Correlations between PTGI Factors: Factor correlation matrix	142

List of Figures

Systematic Review

Figure 1: Literature Review Flow Chart	13
--	----

Journal Article

Figure 1: Social support and PTGI scores by gender and transition	106
Figure 2: BES and REQ scores by gender and care transition group	106
Figure 3: Scree plot of BES factors	140
Figure 4: Scree plot of REQ factors	141
Figure 5: Scree plot of PTGI factors	142

List of Abbreviations

AAP	Adelaide Activities Profile
ANOVA	Analysis of Variance
BES	Basic Emotions Scale
CDR	Clinical Dementia Rating, CDR
CES-D	Centre for Epidemiologic Studies - Depression Scale
FDS	Functional Dementia Scale, FDS
HDRS	Hamilton Depression Rating Scale
IRAS	Integrated Research Application System
MMSE	Mini Mental Status Examination
MSQ	Mental Status Questionnaire
NHS	National Health Service
REACH	Resources for Enhancing Alzheimer's Caregiver Health
REQ	Regulation of Emotion Questionnaire
PCA	Principal Components Analysis
PSS	Perceived Stress Scale
PTGI	Post traumatic growth inventory
PTG	Post traumatic growth
SDCRN	Scottish Dementia Clinical Research Network
SDS	Short Zung Interviewer Assisted Depression Rating Scale
SIGN	Scottish Intercollegiate Guidelines Network

Word Counts

Thesis Abstract	444
Systematic Review	9236
The Research Context	1680
Journal Article	9790
Total Thesis Portfolio	21150

Abstract

Background: Despite evidence that caring for a spouse or partner with dementia may continue over a number of years, our understanding of how the carer's experience unfolds over time is still in its infancy. In addition, the emotional experience of spousal dementia carers has been incompletely understood in research and clinical practice with a predominant focus upon negative emotional consequences. There is a need to contextualise the emotional experience of carers within a framework that enables understanding of positive aspects of the care experience.

Objective: This thesis is in two parts. Part one uses systematic review to critically evaluate evidence from published longitudinal studies that assess the impact of care transition (caring for spouse at home and placed spouse in care home) on the well-being of spousal dementia carers. Part two is an empirical study examining emotion regulation and positive growth in spouses who care for their partner with a diagnosis of dementia.

Methods: Systematic review of longitudinal studies that assess the impact of care transition on spousal carer well-being. The empirical study comprised a cross-sectional design comparing positive growth and emotion regulation in three carer groups (caring for spouse at home, placed spouse in care home or experienced death of spouse). 183 carers were recruited through a postal survey which comprised the following self-report measures: Post Traumatic Growth Inventory; Basic Emotions Scale; and Regulation of Emotions Questionnaire.

Systematic Review Results: Despite poorer psychological and physical well-being over time compared with non-carers, symptoms of depression, perceived burden and stress are stable over time for those who continue to care for their spouse at home. Mixed results are obtained for carer well-being when examining transition to permanent placement in care home and impede definitive conclusions.

Empirical Study Results: Spousal carers report more frequent feelings of fear and frustration compared to other basic emotions. Gender and care transition impact upon the experience and regulation of emotion and positive growth. Internalising emotion regulation strategies (for example, rumination) are associated with greater fear and frustration, sadness and guilt while strategies comprising social support seeking are associated with feelings of happiness in carers. Spouses report positive growth since taking on the role of carer and this is predicted in part by social support seeking emotion regulation strategies but not by experience of emotions.

Conclusions: Spousal carers are not a homogenous group. Further research on the experience of spousal dementia carers is required. This should include the development of tools and methods tailored to capture emotion regulation. The concept of positive growth following stressful events (for example, becoming a carer) may have potential for presenting an enriched understanding of the emotional consequences of the carer experience over time.

1 Systematic review: What happens to spousal dementia carer emotional well-being before and after care home placement?

1.1 Abstract

Background: Despite evidence that caring for a spouse or partner with dementia may continue over a number of years, our understanding of how this unfolds over time is still in its infancy. This systematic review aims to summarise and evaluate evidence from published longitudinal studies assessing the impact of care transition on emotional well-being of spousal carers.

Method: Embase, Medline, PsycINFO, CINAHL and ASSIA were searched between January 1980 and February 2013 for prospective cohort studies of emotional well-being of spousal dementia carers relating to care transitions. Case reports, intervention studies and qualitative studies were excluded from review.

Results: The literature search identified 166 articles of which ten met the criteria for inclusion. Carers have poorer psychological well-being over time compared with non-carers, although symptoms of depression, perceived burden and stress are stable over time for those who continue to care for their spouse at home. Findings were inconclusive within and between studies regarding transition to care home. Poorer emotional well-being and improvement in well-being were associated with permanent placement in five studies. Different outcome measures limit the comparability of studies while relatively short follow-up periods, with infrequent re-interview, restrict understanding of the care experience over time.

Conclusions: Longitudinal studies demonstrate that care placement impacts upon carer well-being, although inconsistent and contradictory results impede definitive conclusions. Spousal carers are not a homogenous group and merit further research using a wider range of study variables to examine carer well-being trajectories over longer periods of time.

Keywords: spouse; carer; depression; emotional well-being; transition; dementia; longitudinal; systematic review.

1.2 Introduction

1.2.1 Dementia

Dementia is a progressive degenerative condition, characterised by behavioural, psychological, physical and cognitive impairments, that affects the personality, mood and behaviour of the person with dementia and impacts upon those who care for and about them (Boss, 2011). The time from diagnosis of Alzheimer's dementia to death may be several years (Sachs *et al.*, 2004) with research highlighting a range from a median of 4 years (Wolfson *et al.*, 2001), (4.2 years for males and 5.3 years for females (Larson *et al.*, 2004)) up to 9 years (Walsh *et al.*, 1990).

1.2.2 Estimates and National priorities

There are an estimated 821,884 people in the UK with dementia (1.3% of the UK population and 20% of those aged over 85 years, Knapp & Prince, 2007) costing £23 billion per year (Luengo-Fernandez *et al.*, 2010). UK predictions suggest a rise in the number of people with dementia to 1.7 million by 2051 (Knapp & Prince, 2007). The number of people with dementia in Scotland is expected to double between 2011 and 2031. The scale and extent of dementia and the reliance upon family, health and social care systems place dementia as a significant public health concern (Scottish Government, 2013).

The Scottish Government have identified dementia as a national priority (Scotland's National Dementia Strategy, 2010; 2013). In the drive to improve systems of dementia care, there is a focus across health boards in Scotland on early diagnosis and identification of dementia; post diagnostic support; and alternatives to hospitalisation. In addition, the need to support carers to maintain relationships and receive psychological support has been outlined in the standards of care (Standards of care for dementia in Scotland, 2011a) and in national guidance that evidences the use of psychological therapies (Scottish Government,

2011b). In the absence of a sound longitudinal dementia carer evidence base, the Scottish Government has given a commitment to providing one year post diagnostic support for dementia carers although it is not known whether the timing and duration of this provision is appropriate, effective or sufficient for the majority of carers.

1.2.3 Dementia care

Dementia care-giving is a dynamic process that may last several years during which time the carer may experience transitional stages such as care home placement (Gaugler *et al.*, 2003a; 2003b) and loss of control associated with unpredictable deterioration in the care recipient (Ory *et al.*, 2000). Dementia progression requires that dementia carers manage a challenging process of psychological adjustment (Pinquart & Sorenson, 2003a) including restructuring roles and systems of decision making (Qualls, 2008).

1.2.4 Psychological well-being in dementia care

The spouse is a key attachment figure (Hazan & Shaver, 1987) and spousal dementia care changes the relationship between spouses including the loss of the person the carer once knew (Shim *et al.*, 2012). Social isolation (Drentea *et al.*, 2006) and emotional loss (Rodriguez *et al.*, 2003) are reactions associated with dementia care. Spousal dementia carers are more likely to experience depression (Adams, 2008; Joling *et al.*, 2010; Pinquart & Sorensen, 2011), burden (Hong & Kim, 2008) and greater age-related health problems than other familial carers (Pinquart & Sorenson, 2007). This may impact negatively upon perceived stress levels (Pinquart & Sorensen, 2003a; 2011).

Higher anxiety and symptoms of depression in the month prior to interview in spousal dementia carers have been found to be associated with the perception that the dementia is impeding the carer's social participation and relationships, with females reporting higher anxiety and males higher depression (Croog *et al.*, 2006). Providing care for a partner with

dementia is associated with distress and challenges exceeding those of other types of spousal care (Schulz & Williamson, 1994). Cross-sectional dementia carer studies highlight negative impacts of caring on psychological health (Schultz *et al.*, 1995), most notably amongst carers who report stress (Schulz *et al.*, 1997; Schultz & Beach, 1999). Carers with high anxiety are likely to experience burden over time while those who report satisfaction with the quality and quantity of social support they receive are less likely to report burden (Vitaliano *et al.*, 1991) and less likely to report symptoms of depression (Waite *et al.*, 2004).

1.2.5 Psychological well-being and gender

A review of gender differences in psychological well-being amongst carers that included spouses with dementia found higher levels of depressive symptoms as measured by the CES-D (a self-report scale designed to measure symptoms of depression in the general population) in female carers in the majority of studies (Yee & Schulz, 2000). Systematic review of familiar carers, including dementia carers, found small yet significant effects of gender on depression and burden with higher depression and burden in female than male carers (Pinquart and Sorensen, 2006a). Cross sectional studies have found that female dementia carers report greater burden than male carers (Barush & Spaid, 1989; Gilhooley *et al.*, 1984; Miller & Cafasso, 1992).

Although greater social and physical burden has been reported in female familial dementia carers compared to males, emotional burden was found to be similar in males and females (Akpınar *et al.*, 2011). In contrast to Yee & Schulz (2000), Gallichio *et al.*, (2002) found that symptoms of depression as measured by the CES-D were similar in male and female carers.

1.2.6 Physical health and dementia care

Ill health in carers has more generally been cited as a reason for permanent care placement (Chenoworth & Spencer, 1986) and associated with the level of disability of the care recipient and the length of time in the carer role (Sneyder & Keefe, 1985). Given the chronic stress involved in dementia caring, it may be expected that higher rates of physical illness will be found in carers (Dougal & Baum, 2012; Thoits, 2010). It is argued that spousal carers neglect their own health, indeed female spouses have been described as “hidden patients” (Fengler & Goodrich, 1979).

1.2.7 Permanent placement in care home

Care home placement is viewed as a major marker of dementia progression (Winblad *et al.*, 2000 as cited in Gaugler *et al.*, 2009a) and described as one of the core problematic decisions to be taken by carers (Livingston *et al.*, 2010) yet understanding of psychological well-being when one’s spouse is in care is limited (Gaugler *et al.*, 2007). Placement is associated with considerable distress amongst carers (Gaugler *et al.*, 2008; 2009b) with increases in spousal carer depression, anxiety (Schulz *et al.*, 2004), sadness and guilt (Rudd *et al.*, 1999) following placement.

Family caregivers often retain an active role in care when residence has transferred to long-term residential care facilities (Brown-Wilson & Davies, 2009) and spouses in particular experience a different set of challenges compared with other familial carers (Zarit & Gaugler, 2006). These include reticence in placing their spouse in care (Montgomery & Koslovski, 1994), providing higher levels of care after placement with greater frequency of visits (Gaugler *et al.*, 2003a; Wright, 1998; Zarit & Gaugler, 2006). Nevertheless, assumptions continue to be made about the benefits of care home placement in reducing demands on the carer (Gaugler *et al.*, 2011).

1.2.9 Variation in carer well-being

Variation in dementia carers' psychological well-being has been noted with some carers improving and some deteriorating following care home placement (Gaugler *et al.*, 2010) although the passing of time has been associated with an increase in well-being (Zarit & Whitlatch, 2002). Systematic review found that a large number of care recipient behaviours were associated with carer well-being although results were inconclusive regarding the link between care recipient behaviours and familial carer depression and burden (Ornstein & Gaugler, 2012).

The differential response to caring, whereby some carers experience marked decline in well-being whilst others do not (Gonzalez *et al.*, 2011), may be best understood by studying care giving prospectively and over the course of transition to care home. The point at which carers may have the space to consider their own psychological needs may be at transition such as care home placement, making this worthy of study.

1.2.10 Understanding the impact of care transition over time

To understand the impact of care transitions such as permanent care home placement, it is important to examine the care experience over time, yet carers are not typically followed up over time (Schulz *et al.*, 2001). A need for greater understanding of the longitudinal course of emotional distress in carers, and a lack of emotionally focussed interventions, was demonstrated in systematic review two decades ago (Knight *et al.*, 1993) yet the evidence base to date consists mainly of cross-sectional studies which are limited in their ability to explain the development of carer experience (Gaugler *et al.*, 2011).

Longitudinal research may inform more meaningfully on the impact of dementia carer emotional well-being over time although research has examined predictors of care home placement rather than the impact that care placement has upon carer psychological well-

being (Gaugler *et al.*, 2011). Mixed results have been reported regarding the impact of familial carer intervention on delayed care home placement. Meta-analyses found that only multi-component intervention (a combination of different forms of intervention) delayed placement (Pinquart & Sorensen, 2006b). Systematic review demonstrated that combined individual and group counselling interventions but not multicomponent psychosocial intervention or individual training delayed placement (Goy & Kansagara, 2010). Longitudinal research found that support intervention, including counselling spousal dementia carers, delayed care home placement in spouses with dementia (Mittelman *et al.*, 2006).

Meta-analysis of familial dementia carer interventions found beneficial effects of psychoeducational and respite intervention upon subjective well-being, burden and depression, while social support intervention improved subjective well-being (Pinquart & Sorensen, 2006b). Systematic review of interventions to support familial carers of people with dementia living in the community found a small, significant positive effect of multi-component and psycho-educational interventions on carer depression but no impact on burden (Parker *et al.*, 2008). Gaugler *et al.*, (2008) found that counselling and support group participation decreased depression and burden after care home placement in familial carers when compared with those who continue to provide care at home.

Systematic review of psychological interventions found that developing skills in managing emotional distress and developing dementia knowledge enabled carers to maintain levels of emotional well-being over time (Elvish *et al.*, 2013). Individual CBT and group-based CBT with familial dementia carers have been found to be effective in treating depression and stress, respectively (Gallagher-Thompson & Coon, 2007).

While a great deal has been learned from dementia carer intervention studies the need for greater understanding of the course of emotional distress in carers who do not receive intervention, identified in the nineties (Knight *et al.*, 1993), has largely been unmet. Some carers experience clinically significant emotional distress such as depression and burden (Gaugler *et al.*, 2010) and may not possess the resources to engage with services and intervention treatment groups. Other carers manage their distress and experience positive aspects of caring for their spouse with dementia (Braun *et al.*, 2009; Searson *et al.*, 2008), most notably where the care role enabled continued spousal connection as part of the marital relationship (Lewis *et al.*, 2005). These carers may be less likely to come to the attention of health services and there is a risk that we miss out on learning from those who adapt in their care role over time.

With an ageing population (Ferri *et al.*, 2006; Knapp & Prince, 2007) there will be an increase in the number of older couples faced with managing dementia progression (Braun *et al.*, 2009). There is a need for greater theoretical and empirical attention to be paid to spousal adaptation; in particular, lessons may be learned from spousal carers who exhibit stable patterns of well-being over time (Martin *et al.*, 2009). There exists an outstanding need, therefore, to study the spousal care experience as it unfolds naturally and without intervention.

1.3 Aims of the study

A systematic review of research published from January 1980 to February 2013 was conducted to identify, quantify and distil what is known about spousal dementia carers' emotional well-being over the course of the care journey and with particular reference to permanent care home placement. This involved a comprehensive search of the literature and critical appraisal of studies for the purpose of providing methodological quality ratings that were comparable between studies. This review will critically appraise and evaluate the

evidence-base examining the impact of care home placement and the emotional well-being of spousal dementia carers in an attempt to answer the following two questions:

1. Is the emotional well-being of dementia carer spouses different to non-carer spouses over time?
2. Is the emotional well-being of spousal dementia carers shaped by care transition?

1.4 Methods

1.4.1 Search strategy

The following databases were searched up to and including 4 February 2013: Embase, Medline, PsycINFO, CINAHL and ASSIA. The search terms used were (spouse* OR spousal OR husband* OR wife OR wives OR couple* OR significant others); (dementia OR Alzheimer's disease); (transition OR trajectory OR stages OR grief OR longitudinal OR prospective OR follow-up). Relevant reviews and references of all included studies were hand searched and authors contacted about other studies and unpublished work.

1.4.2 Selection criteria

Inclusion criteria included all studies that were reported as primary longitudinal quantitative research studies, peer reviewed and published in English, that reported on the impact of transition to care home (an important change event that requires adjustment by carer and spouse with dementia) on spousal carer emotional well-being over time. Well-being was defined through the presence of positive components of the care experience, for example, care uplifts and positive spousal interaction, and absence of depression, burden and stress. Studies which included measures of positive components of care and/or perceived burden, stress or carer depression at baseline and follow-up were, therefore, included in the review. Studies which included baseline measures of carer well-being which were linked with subsequent care transition at follow-up were also included in the review. All dementia carers were residing long term with their spouse at baseline and either continued to reside with their

spouse or placed their spouse in permanent care during the follow-up period. There were no restrictions placed on the type of dementia included in studies selected for review although all care recipient spouses were required to have a formal diagnosis of dementia.

The interest in this review was in the adaptation of spousal dementia carers without intervention because this is less well understood compared to outcomes of carers following intervention which have been examined in a number of large scale programmes (for example, New York Caregiver Programme, Gaugler *et al.*, 2011; Mittelman & Epstein, 2009; and Resources for Enhancing Alzheimer's Caregiver Health (REACH) project, Hebert *et al.*, 2006; Wisniewski *et al.*, 2003). Intervention studies were, therefore, excluded from review.

The following criteria were used to exclude studies that were inappropriate for the purposes of this systematic review: cross-sectional, qualitative and case studies; spousal carer intervention studies; and longitudinal spousal carer studies that did not examine the impact of care transition on emotional well-being. Articles which amalgamated adult child carers with spousal carers were excluded from review.

1.4.3 Quality assessment

The quality assessment rating system was developed by the review author using principles derived from Cochrane Collaboration and SIGN 50 guidelines and primary research non-intervention studies (Kmet *et al.*, 2004) and based upon the quality assessment criteria for reviewing non-intervention studies used by the Eppi-centre (Harden *et al.*, 2001). The methodological quality of included studies was rated on a three-point scale applied to ten criteria (equally weighted, see Table 1, below). The maximum score obtainable was 20 (ten criteria multiplied by score of two). An overall percentage was calculated by dividing the total score (ten criteria multiplied by the score (0, 1 or 2) by total of 20).

Studies were included in the review to inform on the impact of dementia care on emotional well-being over time. Points were awarded to studies that included an appropriate comparison group (important in determining whether it is the care experience or natural passage of time that is impacting on carers) and to studies that included a measure of dementia severity (important in contextualising the stage of dementia and challenges that may present for carers and care recipients). Table 1, below, displays the critical appraisal quality criteria.

Table 1. Quality criteria: definitions for critical appraisal of review articles

1. Study rationale: study rationale was clear and justified
WC: The aims of the study were clearly stated and the context of the study were well described with a clear explanation of, and justification for, the focus of the research and the methods used.
AA: Study aims and objectives were outlined
PA: Lack of clarity of study aims and objectives
2. Theoretical framework: the study was based upon a theoretical framework
WA: The study provides an explicit account of the theoretical framework and/or includes a robust literature review which links the research to an existing body of knowledge.
AA: The study was based upon a theoretical framework and included an adequate literature review
PA: The literature review was inadequate and the study failed to make links between existing body of knowledge and research undertaken
3. Sampling strategy: the study sampling strategy was clear and justified
WC: Clear rationale, justification and description of the circumstances under which the sample was recruited into the study
AA: Sampling strategy and recruitment adequately defined
PA: Lack of clarity in describing how the sample were targeted and recruited into the study
4. Eligibility criteria: the study provides clear details of the sample of spouses used
WC: Inclusion/exclusion criteria for spouses included in the study clearly defined and limitations identified to enable contextualisation of results
AA: Inclusion/exclusion criteria for spouses defined to enable replication
PA: Inclusion/exclusion criteria for spouses poorly defined
5. Comparison group: the study included an appropriate comparison group
WC: Rationale and justification for use of comparison group, inclusion criteria clearly defined, age matched, gender matched, spousal status matched, caregiving status monitored,
AA: Age matched, gender matched, spousal status matched
PA: Use of comparison group unmatched on key features of age, gender and spousal status
NA: Study did not include comparison group
6. Carer outcome measures: robust measures of well-being were used
WC: The measures used to examine well-being have robust validity and reliability for the spouses used in the studies
AA: The measures used to examine well-being have reasonable validity and reliability for the spouses used in the studies
PA: The measures used to examine well-being have questionable validity and reliability for the spouses used in the studies
NA: Well-being for the carer was not addressed using formal measures
7. Care recipient outcome measures: robust measures of well-being were used
WC: The measures used to examine well-being have robust validity and reliability for the spouses with dementia in the studies

AA: The measures used to examine well-being have reasonable validity and reliability for the spouses with dementia in the studies
PA: The measures used to examine well-being have questionable validity and reliability for the spouses with dementia in the studies
NA: Well-being of the spouse with dementia was not addressed using formal measures

8. Data analysis: methods of data analysis were appropriate to the study

WC: A clear and detailed description of methodology, including overall research framework, and use of data collection and data analysis methods that are valid and reliable for longitudinal/prospective data
AA: Adequate and suitable methods used to collect and analyse longitudinal/prospective data
PA: Inadequate methods used to collect and analyse longitudinal data, lacking detail to replicate
NA: Sample size too small for longitudinal analyses

9. Sample size: sample size was sufficient to enable longitudinal follow-up

WC: Attrition rates were reported at each follow-up stage, sample numbers included in analyses were clearly identified and the implications of sample size for analyses discussed
AA: Attrition rates were reported at follow-up
PA: Attrition rates were not reported in enough detail to ascertain sample size at follow-up
NA: Attrition was not addressed

10. Data→ Interpretation: the study included sufficient original data to mediate between data and interpretation

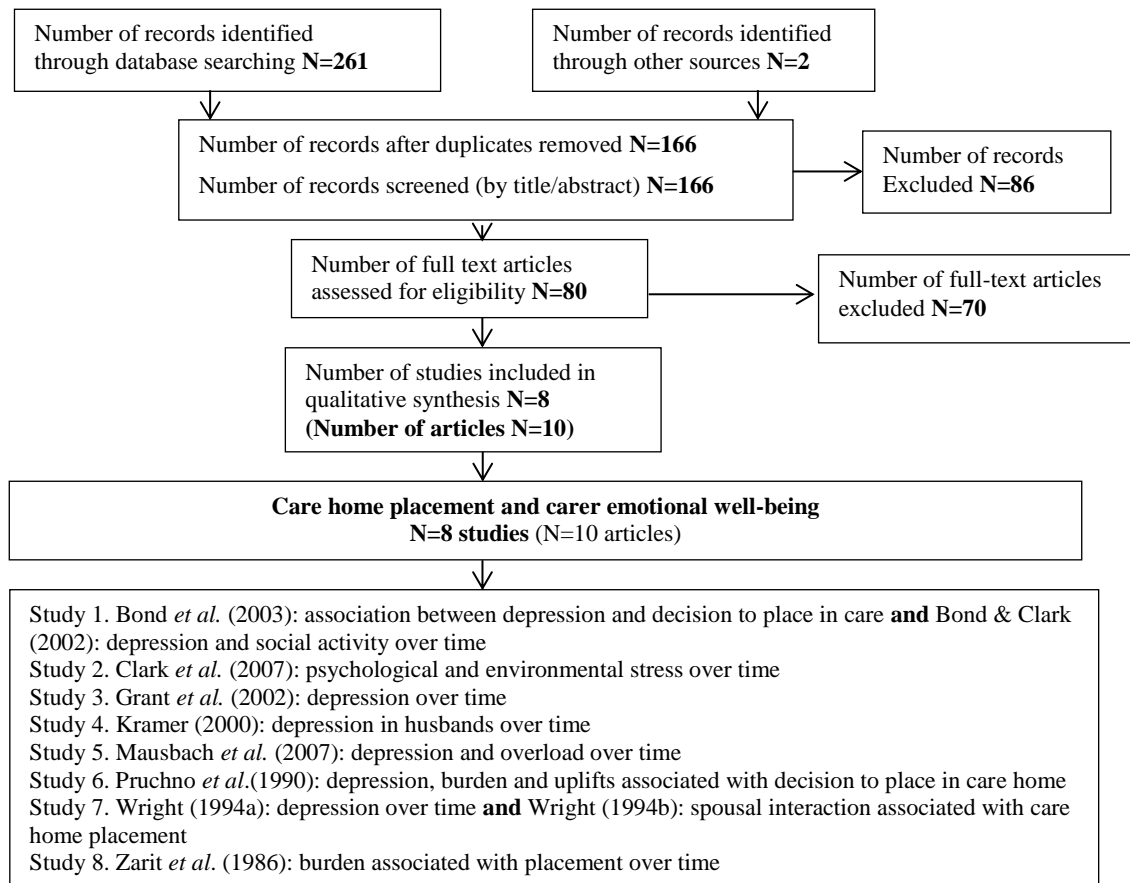
WC: The article presents sufficient data to enable the reader to see that the results and conclusions are grounded in the data. A clear path is identified between the data and the interpretation and conclusions. Consideration is given to the impact of the methods used on shaping the findings of the study to aid interpretation and judgement about the validity and generalisability of findings.
AA: Data reporting is adequate in enabling the reader to see results and conclusions are grounded in the data presented
PA: Data reporting is inadequate in enabling the reader to see that results and conclusions are grounded in the data
NA: Results and conclusions are not grounded in the data provided

Well covered (WC): 2 points (++)	Poorly addressed (PA): 0 point (-)
Adequately addressed (AA): 1 point (+)	Not addressed (NA): 0 point (-)

1.5 Results

1.5.1 Literature Search

The search strategy uncovered 166 studies after removal of duplicates. These were screened by title and reduced further upon examination of the abstract of articles and in some instances by reviewing the full text (Figure 1, below, summarises the review process). Eight separate prospective cohort studies satisfied the main inclusion and exclusion criteria. Information on these eight studies was gathered from ten published articles with four articles providing information about two studies (Bond & Clark, 2002 and Bond *et al.*, 2003: Study 1 and Wright 1994a; Wright 1994b: Study 7). There is a need to differentiate between each published article within study 1 or study 7 where they address a different aspect of a research question. Where each article is cited separately, however, it should be noted that each pair inform only one study.

Figure 1: Literature Search Flow Chart

Please note: number of studies=8, information gathered from 10 published articles

The greatest number of articles were excluded on the grounds that they comprised carer or care recipient intervention studies (n=21), therefore negating the study of the care experience as it unfolds naturally without intervention, or because they amalgamated spousal with other familial or informal carers (n=21) which meant it was not possible to examine spousal responses. The remaining excluded studies were longitudinal studies that did not examine the care transition (n=10), studies whose population was non-dementia carers (n=6), studies whose design was qualitative (n=3), case study (n=2) or cross sectional (n=3) and a study in which the carer status of the spouse was not defined (n=1).

1.5.2 Assessment of study quality

Studies were scored using the criteria outlined in Table 1 and results are presented in summary in Table 2, below. Reviews have used a 60 per cent cut-off score to differentiate studies of higher quality (Luppino *et al.*, 2010; Van der Kooy *et al.*, 2007). Using this cut-off, two studies ranked as 'higher quality' (Bond *et al.*, 2003; Clark *et al.*, 2007), four studies scored 50 - 55 per cent and two studies scored 45 per cent.

Study methodology and quality ratings are summarised in Table 2, p.15, and Table 3, pp. 19 - 26. Tables 4 and 5, pp. 29 - 30, provide a summary of the scales used to assess well-being amongst spousal carers and Table 6, p. 30, to assess care recipients in each study. Table 7, pp. 36 - 42, summarises analyses, findings and conclusions of each study.

1.5.3 Setting and sampling of included studies

Eight prospective cohort studies were included, two were based in Australia and six in the US. Overall, the numbers of spousal carers ranged from 30 to 29 (Wright, 1994a) and 315 to 220 (Pruchno *et al.*, 1990) between baseline and follow-up. Studies recruited through a combination of sources including Alzheimer's association or Alzheimer's disease research organisations, carer support groups and older adults' services.

1.5.4 Coverage of the studies

1.5.4.1 The follow-up period

Follow-up duration varied between and within the eight studies subject to review (Table 3: Methods and Participants). Three studies (Kramer, 2000; Pruchno *et al.*, 1990; Clark *et al.*, 2007) reported follow-up data at one year after baseline interview or assessment and three studies at two years (informed by five articles: Bond & Clark, 2002; Bond *et al.*, 2003; Wright, 1994a; 1994b; Zarit *et al.*, 1986). Two studies followed up spouses more regularly at 6 monthly intervals (Grant *et al.*, 2002; Mausbach *et al.*, 2007).

Table 2. Methodological quality indicators of longitudinal studies that examine caring for a spouse with dementia

FIRST AUTHOR	STUDY RATIONALE	THEORETICAL FRAMEWORK	SAMPLING STRATEGY	ELIGIBILITY CRITERIA	QUALITY CRITERION		CARE RECIPIENT OUTCOME MEASURES	DATA ANALYSIS	SAMPLE SIZE	DATA INTERPRETATION	TOTAL SCORE
					COMPARISON GROUP	CARER OUTCOME MEASURES					
1. Bond (2002)											
Bond (2003)*	++	+	++	+	-	+	+	+	+	++	12 (60%)
2. Clark (2007)	+	+	++	++	++	+	-	+	+	++	13 (65%)
3. Grant (2002)	+	+	+	+	+	+	+	+	+	+	10 (50%)
4. Kramer (2000)	+	++	+	+	-	+	-	+	+	++	10 (50%)
5. Mausbach (2007)	+	+	+	+	-	+	+	+	+	+	9 (45%)
6. Pruchno (1990)	+	++	+	+	-	+	+	+	++	+	11 (55%)
7. Wright (1994a)											
Wright (1994b)*	++	++	+	+	-	+	+	+	+	+	11 (55%)
8. Zarit (1986)	+	-	+	+	-	+	+	+	++	+	9 (45%)
Total score	12 (60%)	12 (60%)	13 (65%)	11 (55%)	4 (67%)	10 (50%)	8 (50%)	10 (50%)	12 (60%)	13 (65%)	
Well covered	2	3	3	1	1	0	1	0	2	3	
Adequately addressed	8	6	7	9	2	10	7	10	9	7	
Poorly addressed	0	1	0	0	0	0	0	0	0	0	
Not addressed	0	0	0	0	7	0	2	0	0	0	

Well covered (WC): 2 points (++)

Adequately addressed (AA): 1 point (+)

Poorly addressed (PA): 0 point (-)

Not addressed (NA): 0 point (-)

* Please note that Study 1 and Study 7 are each informed by two published articles which are jointly assessed in this table. Where they address different aspects of review questions, published articles are cited separately for ease of reference. For example, Wright (1994a) includes a non-carer group to compare depression over time and is used to address review question 1 while Wright (1994b) does not include a comparison group although examines the association between spousal interaction and the association with subsequent care transition and is used to address review question 2. Bond & Clark (2002) examine baseline measures including decision to place in care and their association with care transition status at follow-up while Bond *et al.* (2003) include post-care transition measures which address different aspects of review question 2.

1.5.4.2 Attrition rates

Percentage attrition may be an inappropriately crude measure of study rigour and therefore it is important to contextualise follow-up figures by reference to the study population and assessment methodology (Amico, 2009). In the present review, Grant *et al.*, (2002) purposively selected only those participants with a minimum of three data points (technically zero attrition) while Mausbach *et al.*, (2007) did not report attrition rate. Six studies reported attrition rates with a range from 6 per cent (Clark *et al.*, 2007) to 23 per cent (Kramer, 2000; Pruchno *et al.*, 1990) at one year and from 3 per cent (Wright, 1994b) to 45 per cent (B. Mausbach, personal communication, 25 February 2013) at two years. Attrition rates are summarised in Table 3: Participants.

1.5.4.3 Time between transition and follow-up as a confounding factor

The average duration between care home placement and follow-up was from 5.6 months (SD = 3.4 months), Clark *et al.*, (2007) to 15 months (SD = 7 months), Bond & Clark, (2002). Three studies (Pruchno *et al.*, 1990; Wright, (1994a; 1994b); Zarit *et al.*, 1986) did not report the length of time that had passed between care placement and follow-up. The confounding effect of time on transition outcomes in these studies cannot be examined and makes comparisons difficult.

1.5.4.4 Differences between participants who remain in the study versus drop-outs

Only two studies reported on differences between those who engaged in follow-up and those who were lost to follow-up, finding that those who continued in the study were younger (Bond *et al.*, 2003; Pruchno *et al.*, 1990). Six studies did not examine drop-outs and continued participants (Clark *et al.*, 2007; Grant *et al.*, 2002; Kramer, 2000; Mausbach *et al.*, 2007; Wright (1994a; 1994b); Zarit *et al.*, 1986) which limits interpretation of carer outcomes at follow-up.

1.5.4.5 Age, gender and physical health of spousal carers

The average age and gender of spousal carers (Table 3: Participants) ranged from 67 years (Wright, 1994b) to 74 years (Clark *et al.*, 2007). Gender ratios were most commonly around 65 per cent female: 35 per cent male although ranged from 52 per cent female (Zarit *et al.*, 1986) to 80 per cent female (Wright, 1994b) in seven studies subject to review. One study reported only on male spousal carers (Kramer, 2000) which impedes meaningful comparison with other studies in this review.

Six studies used six different physical health measures that differed in content, structure and administration (Table 5, p. 30). Three of these studies compared carers who continued to live with their spouse with carers who placed their spouse, one of which reported results at baseline only (frequency of illness: Pruchno *et al.*, 1990) and two at baseline and follow-up (physical health status and perceived change in health: Bond *et al.*, 2003; perceived change in health in the preceding year: Kramer, 2000). Two studies compared physical health of carers and non-carers at baseline (Wright, 1994a; Grant *et al.*, 2002) and one study at baseline and follow-up (stress-related physiology measures: Clark *et al.*, 2007). The diversity in measures limits the potential for comparison between studies although enables comparison between carer groups within studies (discussed further in sections 1.5.6.1, p. 31 (review question 1) and 1.5.8.1, p.34 (review question 2)).

1.5.4.6 Length of time in the carer role

There was variation in the reporting of duration of care (Table 3: Participants) with reports of average *length of time in the carer role* (range: 2.8 to 11.1 years, Bond & Clark, 2002; Grant *et al.*, 2002; Pruchno *et al.*, 1990), average *time since diagnosis* (around three years, Bond & Clark, 2002; Clark *et al.*, 2007) and mean *time since symptom onset* (range: 5.2 to 6.5 years, Bond & Clark, 2002; Kramer, 2000; Wright, 1994a; Zarit *et al.*, 1986). One article (Mausbach *et al.*, 2007) did not report length of time in the carer role or symptom onset.

1.5.4.7 Dementia diagnosis

Five studies comprised carers of spouses with a diagnosis of Alzheimer's disease (Bond & Clark, 2002; Clark *et al.*, 2007; Grant *et al.*, 2002; Mausbach *et al.*, 2007; Wright, 1994a). Two studies comprised dementia (Kramer, 2000) and Alzheimer's disease and related disorders (Pruchno *et al.*, 1990). One study included two thirds Alzheimer's disease and one third multi-infarct dementia (Zarit *et al.*, 1986). Variation in population mix needs to be taken into account when comparing between studies. Table 3: Methods.

1.5.4.8 Dementia severity

Five measures of dementia severity (Functional Dementia Scale, FDS, Moore *et al.*, 1983; Clinical Dementia Rating, CDR, Hughes *et al.*, 1982; Geriatric Depression Scale (GDS), Brink *et al.*, 1982; Global Deterioration Scale, Reisberg *et al.*, 1982; Mental Status Questionnaire, MSQ, with Face Hand Test, Kahn *et al.*, 1960) were used only at baseline in five studies (seven articles: (Bond & Clark, 2002; Bond *et al.*, 2003); Grant *et al.*, 2002; Mausbach *et al.*, 2007; Wright (1994a; 1994b); Zarit *et al.*, 1986) which limited comparability between studies (Table 6: Dementia severity scale, p. 30). Three studies (Clark *et al.*, 2007; Kramer, 2000; Pruchno *et al.*, 1990) included no formal measure of the severity or stage of the care recipient's dementia which means that it is not possible to determine if there is an impact of spousal stage of dementia on carer emotional well-being in these studies.

Table 3 Summary of methodology and quality rating for each included study

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 1 Bond & Clark (2002) Predictors of care transition: placing spouse in care home	Recruited spousal carers registered with the Alzheimer's Association of South Australia. Interview with registered carer at home. Follow-up 2 years later: written invitation to participate in follow up, telephone call 1 week later to establish caregiver status. Diagnosis: Alzheimer's Disease.	Country: Australia Spousal carers, co-habiting with and actively providing care at baseline to spouse with geriatrician diagnosis of Alzheimer's disease. Number: 163 >=65 years Mean age: 71 years (SD=7.6 years) 69 male: 94 female (58% female) Mean years providing care: 3.2 (SD=3 years) Follow up: 97% (n=158* carers) (N=60 (32%) continued care at home and N=98 (68%) placed spouse in care home) Number in sample by years since diagnosis: N=46: <= 1 year, N=60: 1- 4 years, N=57: > 4 years Comparison group: no Mean duration between care home placement and follow-up: 15 months (SD=7 months)	Carer status: continued care at home or placement in care home Carer depression Carer activity <i>Dementia severity of care recipient</i>	Carer self-report living arrangements of spouse with dementia Geriatric Depression Scale (GDS) Carers who continued to live with spouse scored below cut-off indicating depression Carers who placed their spouse in care scored above cut-off indicating depression Adelaide Activities Profile (AAP) <i>Functional dementia scale (FDS)</i> <i>Time (years) since diagnosis</i>	10/20 (50%)
Bond <i>et al.</i> (2003) Depression and care transition: placing spouse in care home	Same study as above. Re-interview at home of caregivers 2 years after baseline. Diagnosis: Alzheimer's Disease.	Follow-up interview: 92% (n=150/163) Attrition: 8% 63 male: 87 female (58% female) Mean age carer: 71.3 years (SD=7.4) Mean age care recipient: 74.3 years (SD=6.7) Mean years providing care: 3.2 (3 years) Years of care: continued caregivers: 2.9 years (SD=3.1 years); placed spouse: 3.3 years (SD=3.4 years); placed spouse then widowed: 3.5 years (SD=2 years) Comparison group: no Mean duration between transition and follow up (months): 13.8 months placement (SD=6.9 months)	Carer depression Carer activity	Geriatric Depression Scale (GDS) Carers who continued to live with spouse scored below cut-off indicating depression Carers who placed their spouse in care scored above cut-off indicating depression Adelaide Activities Profile (AAP)	12/20 (60%)

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 2 Clark <i>et al.</i> (2007) Psychological and environmental stress and care placement	Recruited spousal carers associated with a memory clinic in Adelaide and non-caregiving spouses drawn from South Australian electoral database. Data reported are first 2 years of a 3 year study (baseline and follow up). Structured interview and questionnaires. Follow-up: 1 year later. Diagnosis: Alzheimer's Disease.	Country: Australia Participants were spousal carers, co-habiting with and primary caregiver of a spouse with geriatrician diagnosis of Alzheimer's disease. Number: 200 carers comprising:	Carer status: continued care at home or placement in care home	Carer self-report living arrangements of spouse with dementia	13/20 (65%)
		80 new carers (40%): mean time since diagnosis at baseline 0.5 years (SD=3 months) mean age: 73.9 years (52 - 87 years) 30 male:50 female (62.5% female), and	Psychological stress	Perceived Stress Scale (PSS) in the last month Stress	
		120 veteran carers (60%): mean time since diagnosis at baseline: 3.3 years (SD=1.5 years) mean age: 74.2 years (50 - 95 years) 41 male: 79 female (66% female) Comparison group: yes	Environmental stress	Geriatric Social Readjustment Scale Life events stress	
		60 spousal non-carers , mean age: 71.9, 55 - 88 years 19 male: 41 female (68% female) Follow up: 94% carers (88 veteran (29%) and 57 new carers (44%) continued to care at home and 44 (22%) carers placed spouse in care home Attrition: 6% Follow-up: 88% non-carers (n=53), attrition: 12% Mean duration between care home placement and follow up (months):5.6 months (SD=3.4 months)	Care recipient	No direct care recipient outcome measures reported	

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 3 Grant <i>et al.</i> (2002) Depressive symptoms and transition in care through placement of spouse in care home	Recruited as part of the University of California, San Diego (UCSD) Alzheimer's Caregiver Study Wave 1 (1996-2001) longitudinal study on health consequences of Alzheimer's caregiving. Recruited through the University of California, San Diego (UCSD) Alzheimer Disease Research Centre (ADRC) and community support groups or physician referrals.	Country: US Participants were co-habiting and providing care for their spouse with a diagnosis of Alzheimer's disease by neurologist or diagnosis of probable Alzheimer's disease by physician Number: 119 carers Mean age: 70 years, 42 male: 77 female (60% female) Comparison group: yes	Carer status: continued care at home or placement in care home Carer depression	Carer self-report living arrangements of spouse with dementia Hamilton Depression Rating Scale (HDRS) No carers scored above clinical cut-off	10/20 (50%)
	Participants were interviewed at home. Psychosocial information were collected at home by research nurse and psychology research assistant, respectively.	Spousal non-carer: 48 age-matched (24 male: 24 female (50% female))	<i>Care recipient stage of dementia</i>	<i>The Clinical Dementia Rating (CDR) – nurse administered</i>	
	Periodic 6 month assessments thereafter for at least 18 months ranging to 48 months (regardless of any change in caregiver status).	Follow up: 100% , n=119, sample selected for availability of data at minimum of three data points comprising: 38 continued to care at home 28 placement in home 27 placement then death of spouse 26 death of spouse following care at home		<i>The Memory and Behavior Problems Checklist</i>	
	Diagnosis: Alzheimer's Disease.	Mean duration between transition and follow-up: 6 months (except in cases of spousal death where average of 8 months (range 6 - 12 months, no SDs provided))			
		Mean time since diagnosis at baseline: 8.7 years (SD=1 year)			

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 4 Kramer (2000) Continuity and change through care transition (care home placement)	Multi-method recruitment through community agencies, geriatric services, media notices and word of mouth. Semi-structured interview and questionnaires were administered at location of choice of male primary caregivers who were co-habiting with their spouse with a diagnosis of dementia. Follow-up 1 year later to ascertain carer status and condition of spouse with dementia and re-interview carers with a living spouse. Diagnosis: dementia.	Country: US Participants were husbands caring for a spouse with dementia (as diagnosed by a neurologist) at time of baseline interview Number: 74 male spousal carers (100% male) Mean age: 72 years (SD=?) Mean spousal illness: 6.5 years (no SD provided) Comparison group: no Follow-up interview : 77% (n=57/74), 43 caring at home and 14 for spouse in care home, Attrition:23% Carers whose spouses were deceased were not re-interviewed. Mean duration between transition and re-interview not specified	Carer status: care at home or placement in care home Carer depression Carer stress Carer social participation	Carer self-report of living arrangements Centre for Epidemiologic Studies – Depression Scale (CES-D) <i>in the last week</i> Carers who continued to live with spouse scored below cut-off indicating clinical depression Carers who placed in care scored above cut-off for clinical depression Katz Index of Activities of Daily Living (ADL) Memory and Behaviour Problems Checklist (17-item MBPC) with additional perceived stress rating for each item - self-report Self-rated financial concern of caring for wife using three-point scale (<i>not at all/somewhat/a great deal</i>) Self-rated satisfaction with frequency and quality of social-recreational participation	10/20 (50%)
Sample 5 Mausbach <i>et al.</i> (2007) Psychological well-being related to transition in care through placement of spouse in care home	Recruited as part of the University of California, San Diego (UCSD) Alzheimer's Caregiver Study Wave 2 (2001-2006), longitudinal study of psychobiological responses to stress. Referrals were through the University of California, San Diego Alzheimer Disease Research Centre (ADRC), community support groups, health fairs, and media advertisements. Structured interview using questionnaires at home by research nurses. Longest follow-up: 30 months for placement in care home. Diagnosis: Alzheimer's Disease.	Country: US Participants were spousal carers free of serious medical conditions, co-habiting with and providing care for a spouse with a documented diagnosis of Alzheimer's disease. Number: 126 carers (>=55 years) Mean age:73 years (8.7 years) Mean time married: 42 years (16.4 years) 38 male: 88 female (70% female) Comparison group: no Follow-up:38% (n=48/126) of the original sample experienced transition Estimated attrition 25% year 1 and 45% year 2 29 carers placed spouse in long-term care and 19 carers experienced death of spouse Mean duration between transition and follow-up: 7 months after placement and 12 months otherwise (no SDs provided)	Carer status: care at home or placement in care home Carer stress Carer depression <i>Care recipient dementia severity</i>	Carer self-report of living arrangements Pearlin Role Overload scale Hamilton Depression Rating Scale (HAM-D) nurse administered. No data provided on whether carers scored above or below cut-off for clinical depression <i>Clinical Dementia Rating (CDR) scale administered by nurse</i>	9/20 (45%)

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 6 Pruchno <i>et al.</i> (1990) Predictors of care transition (placement in care home)	Recruited as part of a longitudinal study of 315 spouses in Philadelphia Participants were sought through public announcement and community service and support groups, hospitals, synagogues and churches. Structured interview using questionnaires and rating scales at baseline were repeated a year later at follow-up interview with additional questions on carer status (continue to care at home and spouse institutionalised). Diagnosis: Alzheimer's disease and related disorders.	Country: US Participants were spousal carers, co-habiting with and providing care for a spouse with a diagnosis of dementia Number: 315 spousal carers (male: female 68% female). Mean age: 69 years (range 45 – 94 years, SD=?) Mean length of care: 2.8 years (range 1 month - 20.3 years SD=?) Follow-up: 220 spousal carers (70%) Comparison group: no N=152 continue to care at home, 48% N=68 spouse institutionalised, 22% N=72 lost to follow up, 23% attrition N=23 spouses died 7% -not included in follow-up Significant difference in age and education of follow up group compared with those interviewed at baseline and lost to follow-up Mean duration between care home transition and follow-up not specified	Carer status: continued care at home or placement in care home Carer depression Carer perception of quality of relationship Carer perception of burden Caregiver perception of positive components of caring Care recipient behaviour as rated by carer Carer plans to institutionalise	Carer self-report living arrangements of spouse with dementia Centre for Epidemiologic Studies – Depression Scale (CES-D, 20-item) Carers who continue to live with spouse scored below clinical cut-off for depression at baseline Carers who placed spouses in care scored above cut-off at baseline indicating clinical depression Current quality of relationship: self-report Carer experience checklist (17-item) Carer experience rating (8-item) Frequency of spouse behaviours associated with dementia (34 item) in the month prior to interview Carer actions relating to institutionalisation checklist (7-item)	11/20 (55%)

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 7 Wright (1994a)	<p>Purposive recruitment through agencies (Alzheimer's Disease associations or private physician offices) and churches in two South Eastern states.</p> <p>Formal diagnosis of probable Alzheimer's disease with spouse as primary caregiver.</p> <p>All couples were interviewed in their homes using semi-structured interview at baseline in 1987/1988.</p> <p>Follow-up two years later by phone to ascertain living arrangements and gain approval for postal questionnaire with repeat of scales and questions used at initial interview.</p> <p>Diagnosis: Alzheimer's Disease.</p>	<p>Country: US</p> <p>Participants spouse carers co-habiting with and primary carer of spouse in early-middle phase of Alzheimer's disease and 'relatively healthy' non-carer spouse couples (those with common medical conditions were accepted into the study e.g. arthritis) where both spouses were without cognitive impairment</p> <p>Number: 30 spousal carers Mean age: 67 years (SD=?, 51 - 81 years) 6 male: 24 female (80% female)</p> <p>Mean length of marriage: 38 years (SD=11.7 years, range 6 - 57 years)</p> <p>Mean length of dementia symptoms: 4.8 years (range 1-11 years)</p> <p>Follow up: carer status (living arrangements) information available for 100% of sample (n= 30 carers). Follow-up interview information obtained from</p> <p>Comparison group: 17 non-carer spouse couples, relatively healthy although common medical conditions were accepted into the study</p> <p>Mean length of marriage: 44.8 years (SD=?)* *significantly higher than mean length of marriage in carer group</p> <p>Mean duration between transition and follow-up not specified</p>	<p>Carer status: continued care at home or placement in care home</p> <p>Carer depression</p> <p><i>Care recipient functioning</i></p>	<p>Carer self-report living arrangements of spouse with dementia</p> <p>Short Zung Interviewer Assisted Depression Rating Scale (10-item)</p> <p>No carers scored above clinical cut-off for depression</p> <p><i>Mini Mental Status Examination (MMSE) and Global Deterioration Scale</i></p>	10/20 (50%)

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 7 Wright (1994b) Spousal interaction and care transition through placement of spouse in care home	Same study as above. Purposive recruitment through agencies (Alzheimer's Disease associations or private physician offices) and churches in two South Eastern states. Formal diagnosis of probable Alzheimer's disease with spouse as primary carer. All couples were interviewed in their homes using semi-structured interview at baseline in 1987/1988. Follow-up two years later by phone to ascertain living arrangements and gain approval for postal questionnaire with repeat of scales and questions used at initial interview.	Country: US Participants spouse carers co-habiting with and primary carer of spouse in early-middle phase of Alzheimer's disease Number: 30 spousal carers Mean age: 67 years (SD=?, 51 - 81 years) 6 male: 24 female (80% female) Mean length of marriage: 38 years (SD=11.7 years, range 6 - 57 years) Mean length of dementia symptoms: 4.8 years (range 1-11 years) Mean GDS: 4.4 (range 2 - 6 years) Follow up: carer status (living arrangements) information available for 100% of sample (n= 30 carers). Follow-up interview information obtained from 29 carers, attrition: 3%	Carer status: continued care at home or placement in care home Carer depression Spousal interaction	Carer self-report living arrangements of spouse with dementia Short Zung Interviewer Assisted Depression Rating Scale (10-item) No carers scored above clinical cut-off for depression Dyadic Marital Adjustment Rating Scale (cohesion; tension; affection; overall marital happiness and commitment to future of the relationship, subscales)	11/20 (55%)
	Diagnosis: Alzheimer's Disease.	Comparison group: data not used in this article Mean duration between transition and follow-up not specified	Care recipient functioning	Mini Mental Status Examination (MMSE) and Global Deterioration Scale	

Table 3 Summary of methodology and quality rating for each included study (Continued)

STUDY	METHOD	PARTICIPANTS	CARER OUTCOMES	OUTCOME MEASURES	METHODOLOGICAL QUALITY
Sample 8 Zarit <i>et al.</i> (1986) Perception of burden and care transition (care home placement)	Recruitment of spousal carers through Alzheimer's disease advocacy group membership and carer counselling and support clinic for burden study. Semi-structured interview and questionnaires were administered at home. Participants contacted at follow-up 2 years later to ascertain carer status and request repeat interview with carers whose spouse was still living. Additional questions were asked about the factors affecting the decision to place spouse in a care home at time 2. Diagnosis: two thirds Alzheimer's disease and one third multi-infarct dementia.	Country: US Participants were spousal carers, co-habiting with and providing care for their spouse whose symptoms met DSM-III criteria for dementia (a third multi-infarct dementia, two thirds probable Alzheimer's type) Number: 63 spousal carers, 31 male:33 female (52% female) Mean age: male: 72 years (SD=6.72), female: 63 years (SD=7.48) Mean length of marriage (at initial interview): male:43 years (SD=6.96), female: 36 years (SD=12.26) Follow up: carer status (living arrangements) information available for 91% of carers (n=58/64) Follow up interview information obtained from 82% of carers (n=53/64), attrition: 17% Follow up N=58 (91%) Living with N=32 (50%) Placed in care N=11 (23%) Bereaved N=15 (17%) not included in follow up measures Lost N=6 (9%) Comparison group: no Mean years of memory loss: males: 5.6 years (no SD given) and females: 5.9 years (no SD given)	Carer status: continued care at home or placement in care home Carer burden Carer perception of quality of relationship and social support Carer decisions to place in care home <i>Care recipient</i>	Carer self-report living arrangements of spouse with dementia Burden interview (20-item) Structured interview Open-ended questions regarding what led to decision to place <i>Mental State Questionnaire and Face-Hand test Memory and Behavior Problem Checklist (28-item)</i>	9/20 (45%)

1.5.5 Emotional well-being: measures

1.5.5.1 The focus on measurement of negative outcomes

As outlined in Table 4, pp. 29 - 30, the main carer well-being measures used in the eight studies were symptoms of depression, perceived burden and stress. The findings of the present review are, therefore, largely restricted to examining well-being of spousal dementia carers over time as defined by the absence of negative consequences than understanding positive aspects of the care experience. Pruchno *et al.*, (1990) examined positive components of caring and Wright (1994b) assessed spousal interaction and general marital happiness (discussed further in section 1.5.8.4).

1.5.5.2 Depression measures

Measures of depression were included in six studies (Bond & Clark, 2002; Grant *et al.*, 2002; Mausbach *et al.*, 2007; Kramer, 2000; Pruchno *et al.*, 1990; Wright, 1994a, Table 4: Depression) with four different scales; the Geriatric Depression Scale (GDS, Brink *et al.*, 1982; Yesavage *et al.*, 1983), Centre for Epidemiologic Studies - Depression Scale (CES-D, Radloff, 1977), Short Zung Interviewer Assisted Depression Rating Scale (SDS, 10-item, Zung, 1965) and the Hamilton Depression Rating Scale (HDRS), Hamilton, (1960), a clinician administered semi-structured interview (See Table 4: Depression).

The HDRS, CES-D, GDS and SDS use different response time frames: “the past week” (CES-D and HDRS), “past two weeks” (GDS), and “recently” (SDS), (Burns *et al.*, 2002; Mui *et al.*, 2002; Mulrow *et al.*, 1995). Problems with mood vary depending upon the time frame examined (Teri *et al.*, 1997) and the use of different scales which examine different time frames creates difficulties in comparing depression between studies. The different focus upon affective and somatic symptoms in each scale (Lyness *et al.*, 1997, Sharp & Lipsky, 2002) and under-reporting of depressive symptoms by older adults may impact upon the relative accuracy and comparability of symptoms of depression (Arean *et al.*, 1997).

1.5.5.3 Burden and stress measures

Two studies (Pruchno *et al.*, 1990; Zarit *et al.*, 1986) used self-report burden scales although one was not validated (Pruchno *et al.*, 1990), thereby limiting comparability. In addition, the utility of carer burden as an indicator of carer well-being has been questioned in clinical practice with calls for the use of more clinically relevant measures such as depression when assessing well-being amongst dementia carers (Black & Almeida, 2004). Carer stress was examined in five studies using six different scales covering variable time frames of one week up to three years (See Table 4: Stress and Burden, p.29) and examining different aspects of carer experience (for example the perception of stress more generally in the last month, PSS as used by Clark *et al.*, (2007) compared with general carer fatigue using the Pearlin Role Overload Scale, as used by Mausbach *et al.*, (2007)). This restricts comparisons between studies.

1.5.5.4 Social support measures

Frequency of social support was measured by Zarit *et al.*, (1986) and husband's satisfaction with social participation was recorded by Kramer, (2000), using bespoke and non-comparable frequency and satisfaction ratings (Table 4: Social support). The Adelaide Activities Profile (AAP, Clark & Bond, 1995) was used in one study to measure frequency of lifestyle activities (including social activities) undertaken in the last three months (Bond & Clark, 2002; Bond *et al.*, 2003). Although validated for use in older adults living in the community with adequate validity and reliability, the AAP has not been validated for use in dementia carers who may represent a unique group given the challenges of providing daily care. The retrospective time frame of three months would seem lengthy in the life of some dementia carers.

Table 4. Carer outcome measures: emotional well-being

SCALE USED TO MEASURE CARER OUTCOMES	STUDY FIRST AUTHORS
Depression	
Centre for Epidemiologic Studies – Depression Scale (CES-D, Radloff, 1977) 10-item	Kramer, 2000; Pruchno 1990
Geriatric Depression Scale (GDS, Brink <i>et al.</i> , 1982; Yesavage <i>et al.</i> , 1983)	Bond 2002; 2003
Hamilton Depression Rating Scale HDRS (clinician administered, Hamilton, 1960)	Grant 2002; Mausbach 2007
Short Zung Interviewer Assisted Depression Rating Scale (10-item, Zung, 1965)	Wright (1994; 1994b)
Stress and Burden	
Perceived Stress Scale (PSS, Cohen <i>et al.</i> , 1983) -14 item in the last month	Clark 2007
Geriatric Social Readjustment Scale (Amster & Kraus, 1974) - 35 life events in the last three years	Clark 2007
Katz Index of Activities of Daily Living 7-tasks (Katz <i>et al.</i> , 1963) (with perceived stress rating: 0 - 3 (not at all stressful to extremely stressful))	Kramer 2000
Independent living 8 tasks (with perceived stress rating: 0 - 3 (not at all stressful to extremely stressful*) or perceived input (much/some/none help required+) and Activities of Daily Living 7 tasks with perceived input (much/some/none help required+)	*Kramer 2000; +Pruchno 1990
Memory and Behavior Problem Checklist (Zarit & Zarit, 1987) 17-item with perceived stress rating 0 - 3 (not at all stressful to extremely stressful) in the past week	Kramer 2000
Memory and Behavior Problem Checklist (Zarit <i>et al.</i> , 1980) 29-item with perceived tolerance rating (4-point scale: I can tolerate this behaviour when it occurs to I can no longer tolerate this behaviour and have to do something about it) in the past week	Zarit 1986
Bespoke 34-item problem behaviour checklist: 5-point frequency rating (never/1-2 times a month/3-4 times a month/2-5 times a week/almost daily) in the past month	Pruchno 1990
Pearlin Role Overload scale (4-item global) (Pearlin <i>et al.</i> , 1990)	Mausbach 2007
Bespoke 17-item burden scale (based on Cantor, 1983; George & Gwyther 1986, Zarit <i>et al.</i> , 1986)	Pruchno 1990
Validated Burden Interview 20-item (Zarit <i>et al.</i> , 1980)	Zarit 1986
Lifestyle and physical activities	
Adelaide Activities Profile (AAP, Clark & Bond, 1995)	Bond 2002; 2003
Social support	
Self-report frequency of informal and formal social support (weekly contacts) with 4-point quality rating (4: I get most of the help I need to 1: I feel overwhelmed and do not know where to turn)	Zarit 1986
Self-report satisfaction with social-recreational participation (bespoke frequency and quality ratings of: phone contact, visits with family and friends, personal hobbies, relaxing, club attendance and church attendance) no time frame indicated	Kramer 2000

SCALE USED TO MEASURE CARER OUTCOMES	STUDY FIRST AUTHORS
Positive aspects of care	
Frequency of positive spousal interaction (Dyadic Marital Adjustment Rating Scale, Spanier & Thompson, 1982) 6-point rating (more than once a day to never) and overall marital happiness rating current and prior to dementia (7-point rating: extremely unhappy - perfectly happy)	Wright 1994
Bespoke questions on carer uplifts: how often in the past month carer felt their input keeps spouse from getting worse and how often care recipient provided e.g. companionship/embraces/enjoyment (3-point scale ratings: most or some of the time or not at all)	Pruchno 1990
Quality of marital relationship: current marital quality rating 4-point (poor/fair/good/excellent)	Pruchno 1990
Quality of marital relationship: before dementia marital quality rating 10-point (poor-excellent)	Zarit 1986

Table 5. Carer physical health measures

SCALE USED TO MEASURE CARER PHYSICAL HEALTH	STUDY FIRST AUTHORS
Physical Health	
SF-36 Health Survey and 5-point global health self-rating (excellent – poor) and 5-point perceived health decline in the preceding year (much better – much worse)	Bond 2002; Bond 2003
Multiple Assessment Instrument (MAI)	Wright 1994a; 1994b
Interval Medical History (IMED) and hospitalisation history	Grant 2002
Physiology measures (blood pressure, cholesterol and stress hormones)	Clark 2007
Self-report Illness checklist (12-item)	Pruchno 1990
Self-rating: 3-point scale better/about the same/worse than in the preceding year	Kramer 2000

Table 6. Care recipient outcome measures

SCALE USED TO MEASURE CARE RECIPIENT BEHAVIOUR	STUDY FIRST AUTHORS
Dementia severity/stage of dementia	
Functional dementia scale (FDS)	Bond 2002
The Clinical Dementia Rating (CDR) – nurse administered	Grant 2002; Mausbach 2007
Mental State Questionnaire (MSQ) and Face-Hand test	Zarit 1986
The Memory and Behavior Problems Checklist	Grant 2002; Mausbach 2007; Zarit 1986; Kramer, 2000
Frequency of spouse behaviours associated with dementia (bespoke 34 item rated by carer) in the month prior to interview	Pruchno 1990
Mini Mental Status Examination (MMSE) and Global Deterioration Scale	Wright (1994a; 1994b)
Lifestyle activities	
Adelaide Activities Profile (AAP)	Bond 2002

1.5.5.5 Positive dementia care outcome measures

Two studies (Pruchno *et al.*, 1990; Wright, 1994b) examined positive aspects of care using different measures. Wright (1994b) examined daily ratings of positive spousal interaction and general marital happiness currently and prior to dementia (Dyadic Marital Adjustment Rating Scale, Spanier & Thompson, 1982). Pruchno *et al.*, (1990) examined ratings of positive components of caring in the last month and of current relationship quality (using bespoke, non-validated rating scales). Zarit *et al.*, (1986) also examined relationship quality prior to dementia (bespoke scale), see Table 4: Positive aspects of care, p.30.

1.5.6 Emotional well-being: outcomes relating to review question 1

1.5.6.1 Spousal carers compared with spousal non-carers

Non-carer spousal comparison groups used in three studies reported similar age, gender and marital status to spousal carers (Clark *et al.*, 2007; Grant *et al.*, 2002; Wright, 1994a). Two of these studies reported on socioeconomic status and education levels (no significant differences between carers and non-carers: Wright, 1994a; and “slightly higher” socioeconomic status in the non-carer group (Grant *et al.*, 2002). Similar levels of physical health (Wright, 1994a) and physical symptoms were reported by carers and non-carers at baseline (Grant *et al.*, 2002) although no comparisons were reported at follow-up. Physiological measures of stress were similar at baseline although higher levels were recorded in the carer group at follow-up (Clark *et al.*, 2007). One study reported on length of marriage (significantly shorter in the carer than non-carer group due to second and third marriages, Wright, 1994a, Table 3: Participants).

1.5.6.2 Spousal carers compared with spousal non-carers: depression outcomes

Carers reported higher depression scores than non-carers at baseline and over time in two studies that compared depressive symptoms using two different measures (HDRS, Grant *et al.*, 2002; SDS, Wright, 1994a, Table 7: Findings).

1.5.6.3 Spousal carers compared with spousal non-carers: burden and stress outcomes

Higher stress appraisal and frequency of stressful life events were found in carers at baseline and follow-up (Clark *et al.*, 2007), see Table 7: Findings for a summary of results. No studies compared carers with non-carers using measures of burden or overload.

1.5.7 Emotional well-being: outcomes relating to review question 2

1.5.7.1 Carers who continue to live with their spouse: depression outcomes

Five studies reported stable depression ratings over time in carers who continued to care at home compared with those who experienced transition (Bond *et al.*, 2003; Grant *et al.*, 2002; Mausbach *et al.*, 2007; Kramer, 2000; Wright, 1994a). Mausbach *et al.*, (2007) found higher symptoms of depression in females than males over time.

1.5.7.2 Carers who continue to live with their spouse: burden and stress outcomes

In the absence of any change in frequency of behaviour problems, spouses who continued to care at home showed decreased burden and increased tolerance for memory and behavioural problems at follow-up (Zarit *et al.*, 1986). Clark *et al.*, (2007) found that perceived stress remained at the same level for carers who continued to live with their spouse (Table 7: Findings).

1.5.7.3 Carers who continue to live with their spouse: social support outcomes

Satisfaction with social activities (Kramer, 2000) and self-reported level of social activity (Bond *et al.*, 2003) remained stable in those carers who continued to provide care at home, albeit at significantly lower levels than age normed older adults living in the community (Bond *et al.*, 2003, Table 7, Findings).

1.5.7.4 Carers who experience permanent care home placement: depression outcomes

Three studies demonstrate that care home admission is associated with higher depression in carers who placed their spouse, with depression above clinical cut-off (Pruchno *et al.*, 1990; Bond & Clark, 2002) and a significant rise in depression following placement where spouses subsequently died within 6 months (Grant *et al.*, 2002). Mausbach *et al.*, (2007) found a reduction in carer depression symptoms six to twelve months after placement of spouse in care. Two studies reported insufficient numbers to detect statistically significant change in depression scores following placement (Kramer, 2000; Wright, 1994a). Kramer (2000) reports that depression scores (CES-D) were above the cut-off for depression in a half of husbands who had placed their spouse and a third who continued to care at home.

1.5.7.5 Carers who experience permanent care home placement: burden and stress

Pruchno *et al.*, (1990) and Zarit *et al.*, (1986) found higher burden scores at baseline in carers who subsequently placed their spouse in care by follow-up at one and two years, respectively, which decreased significantly following transition (Zarit *et al.*, 1986). Clark *et al.*, (2007) report a significant increase in life events stress (in the last three years) yet a significant decrease in perceived stress in carers who placed their spouse in care. Kramer (2000) found a reduction in perceived stress (in the last week) relating to activities of daily living reported by husbands who had placed their spouse in care. Mausbach *et al.*, (2007) report reductions in overload after placement. Table 7: Findings.

1.5.7.6 Carers who experience permanent care home placement: social support

Bond *et al.*, (2003) found significantly lower social activity at baseline in carers who went on to place their spouses in care compared with carers who continued to live with their spouse (all carers were significantly lower than age normed levels) while Zarit *et al.*, (1986) reported that availability of social support did not impact upon the decision to place one's spouse in care. After transition, Kramer (2000) found an increase in satisfaction with social

and recreational activities for husbands who placed wives in care and Bond *et al.*, (2003) found a significant increase in social activity in carers who placed their spouse in care (equivalent to age normed group).

1.5.8 Comparisons between carers who live with and carers who place spouses in care

1.5.8.1 Demographic, health and commitment comparisons

Five studies compared carer demographics recorded at baseline between carers who continue to live with their spouse and those who experience permanent care home placement by follow-up. Four studies reported no statistical differences between these two groups of carers in age, gender (Clark *et al.*, 2007) and socioeconomic status (Grant *et al.*, 2002; Kramer, 2000; Pruchno *et al.*, 1990). As outlined in Table 7: Findings, p. 36 - 42, however, spouses who continued to care at home were younger than those who placed spouses in a care home (Bond *et al.*, 2003; Pruchno *et al.*, 1990) with greater commitment to the future of the relationships and more positive spousal interactions (Wright, 1994b).

Four studies found no difference in baseline physical health between carers who continue to live with their spouse and those who experience care home placement by follow-up, as measured by frequency of illness (Pruchno *et al.*, 1990), physical health score (Bond *et al.*, 2003), perceived change in health in the preceding year (Bond *et al.*, 2003; Kramer, 2000) and stress-related physiology measures (Clark *et al.*, 2007). Bond *et al.*, (2003) and Kramer (2000) found that carers who placed their spouse perceived improvements in their health at follow-up whereas carers who continued to live with their spouse did not. Bond *et al.*, (2003) found no differences between carer groups at follow-up in physical health scores.

1.5.8.2 Inconsistent findings: dementia severity and care home placement

Only three studies examined care transition and dementia severity. Bond *et al.*, (2003) found that recipients who remained at home had lower dementia severity scores, in contrast to

Wright, (1994b) and Zarit *et al.*, (1986) who found no association between dementia severity scores and care placement. Continued care at home was more accurately predicted in statistical models than care home placement (Pruchno *et al.*, 1990; Wright 1994b).

1.5.8.3 Inconsistent findings: care home placement and clinical levels of depression

Spousal carers who had experienced care transition scored above the cut-off indicating depression in three studies (using the GDS: Bond & Clark, 2002; Bond *et al.*, 2003, the CES-D: Kramer, 2000; CES-D, Pruchno *et al.*, 1990). See Table 7: Findings. Two studies found that no carers scored above the clinical cut-off for depression (using the Hamilton Depression Rating Scale (HDRS): Grant *et al.*, 2002, and the Short Zung Interviewer Assisted Depression Rating Scale (SDS): Wright, 1994a; 1994b).

1.5.8.4 Positive aspects of caring for one's spouse with dementia

One study found that spouses who continued to care at home at two year follow-up reported greater positive spousal interactions, higher current marital happiness and commitment to the future of the relationship at baseline compared with those who placed their spouse in care by follow-up although no differences were found in ratings of past marital happiness or current affection and tension between carers at different stages of transition (Wright, 1994b). Pruchno *et al.*, (1990) found that carers who continued to care at home at follow-up reported more uplifts in the month prior to baseline interview such as embraces with spouse, enjoyment, and companionship than those who placed their spouse in care.

Regarding quality of marital relationship ratings at baseline, no differences were found between carers who placed their spouse and carers who continued to care for their spouse within the following year (Pruchno *et al.*, 1990 current marital quality ratings) or within the following two years (Zarit *et al.*, 1986, marital quality ratings before dementia). See Table 7, Findings, pp. 39 - 42.

Table 7 Summary of analysis, results and conclusions of studies included in the systematic review

STUDY (FIRST AUTHOR)	STATISTICS TESTS	FINDINGS	CONCLUSIONS
Bond (2002)	<p>N = 163, 58% female</p> <p>2 year follow-up N = 158 58% female</p> <p>Placed in care N = 98 (62%) Living with spouse N=60(38%)</p> <p>Univariate tests of significance (t-tests and chi-squared tests)</p> <p>Logistic regression analyses and odds ratio calculations for carer and care recipient characteristics</p> <p>Logistic regression analyses to determine any predictors of care home placement independently of dementia severity</p>	<p>Baseline: Baseline measures were conducted in 163 carers and differences were examined retrospectively by care transition as assessed at time 2 follow-up.</p> <p>Time2 carer status comparisons: Carers who placed spouse in care home by time 2 report higher depression at time 1 (Geriatric Depression Scale, above clinical cut-off 11.2), greater use of respite services in three months prior to interview and less social activities (Adelaide Activities Profile) than carers who continued to care at home. Carers who placed their spouse in care were older than continued carers and were caring for spouses with greater dementia severity.</p> <p>Care placement was associated with greater dementia severity, lower levels of care recipient activity in the household. After controlling for dementia severity, only age and gender of carer/care recipient were significantly associated with care placement.</p> <p>Female carers more likely than males to place in care if perceived that spouse showed reduced activity in household.</p>	<p>Degree of transition occurring within the study marked two years as a long time in the spousal dementia career.</p> <p>Care recipient features: low household activity levels are associated with transition to care.</p> <p>Severity of dementia was identified as the key reason for transition to formal care.</p> <p>Carer features: older age, reduced social activity and depression are associated with transition to formal care. It is acknowledged that unmeasured age-related co-morbidities rather than age per se may account for age effects reported.</p>
Bond (2003) Sample used in Bond (2002), above	<p>N = 163</p> <p>2 year follow up N = 150 58% female</p> <p>Living with spouse N=60 (40%) Placed in care N = 53 (25%) Bereaved N = 37 (35%)</p> <p>Chi-squared tests, one way ANOVA</p> <p>Independent-samples t tests (with Bonferroni correction) at baseline</p>	<p>Baseline: Dementia severity was not included in analyses in this article given predictive for care transition (Bond, 2000). Social activities (Adelaide Activities Profile, AAP) in all carers were significantly lower than the norm in community dwelling older adults at time 1.</p> <p>Time 1 - Time 2: depression scores (GDS)</p> <p>Carers lost to follow-up at time 2: GDS scores were above clinical cut-off for depression at time 1 (11.3, SD=6)</p> <p>There is no statistical difference in depression scores of carers who continue to care at home or who place in care time 1 – time 2:</p> <p>Carers who continue to care for spouse at home remained below</p>	<p>Four in ten carers continued to care for their spouse at home two years later and over a third placed their spouse in care and a quarter were widowed, highlighting the transition that occurs within this time frame for spousal dementia carers. Authors note that the study was not designed to examine population incidence of care transition and transition proportions are particular to their sample (recruited through the Alzheimer's Association).</p> <p>For those spouses continuing to care at home, depression below clinical cut-off and low levels of social activity remained stable over two years.</p> <p>Carers who placed in care home remained above clinical cut-off for depression and reported a significant increase in social activities to normal</p>

	<p>Repeated measures multivariate ANOVA (time 1 vs time 2), caregiver status as between subjects factor and gender as covariate</p> <p>Post hoc tests: related-samples t tests (Bonferroni correction)</p> <p>activity and psychological well-being</p> <p>Hierarchical multiple regressions controlling for gender effect analysed trajectories of change in widowed carers and those whose spouses resided in care home</p>	<p>clinical cut off (8.8 (SD=6.2) - 9.8 (SD=5.8))</p> <p>Carers who placed their spouse in care remained at clinical cut-off for depression (11.4 (SD=6.4) - 10.3 (SD=7.2))</p> <p>Trajectories of change analyses revealed significant association between longer time since spouse placed in care and lower depression scores.</p> <p>Time 1 – Time 2: social activity scores (AAP) for carers</p> <p>Social activity levels of carers lost to follow up (19.2, SD=15.5) was below normed levels for elderly community dwelling adults (norm=50, SD=20).</p> <p>Carers who placed their spouse by time 2 report a significant increase in social activity at Time 2 to normed levels: (26 (SD=17.6) - 52 (SD=22.7)).</p> <p>Carers who continue to care for spouse at home remained below normed levels at time 2 (32 (SD=18.7) - 30 (SD=20.7))</p>	<p>levels after transition.</p> <p>Lack of improvements in depression symptoms associated with care placement demonstrates the sense of carers life being on hold when spouse is alive and in care home.</p> <p>Authors argue that it may be informative to use a life transitions approach to examine the experience of spousal dementia care in which positives and negatives are associated with transitions the care process.</p>
Clark (2007)	<p>N = 200 63% Female</p> <p>New carer = 80</p> <p>Veteran carer = 120</p> <p>Non carer = 60</p> <p>1 year follow up N = 189</p> <p>Living with spouse: 145 (72%) [new carer = 57 (28%)] [veteran carer = 88 (44%)]</p> <p>Placed in care = 35 (17%)</p> <p>Bereaved = 9 (5%)/Lost = 6%</p> <p>One-way ANOVA at baseline and repeated-measures ANOVA to examine change in variables for carers at time1 and time2.</p>	<p>Baseline: Carers report higher appraised stress (Perceived Stress Scale) and higher environmental stress (life events, Geriatric Social Readjustment Scale) than non-carers.</p> <p>Time 1 to Time 2 comparisons</p> <p>Carers who placed spouses in care report significant increase in life events score yet significantly lower psychological stress at time 2.</p> <p>There was no significant change in psychological stress (PSS) for carers who continued to live with their spouse at home.</p> <p>There was no correlation between environmental and psychological stress ratings and time since placement.</p>	<p>Chronic stress is associated with caring for a spouse with dementia and the transitions that take place.</p> <p>There was a significant increase in life events stress for carers who placed their spouse in care which authors argue reflects the demands surrounding care home admission. In contrast, a significant decrease in appraised or psychological stress was found at follow-up which authors argue may reflect the heightened stress levels in the lead up to relinquishing care.</p> <p>Environmental and psychological stress should be distinguished analytically.</p>

Grant (2002)	<p>N = 119 with three data points over 18 months were chosen from data set for follow up 60 % Female</p>	<p>Baseline: carers have significantly higher depression scores (Hamilton Depression Rating Scale) than non-carers although below clinical cut-off for depression.</p>	<p>Care transition placement are associated with improvement in carer depression symptoms over time although not for spouses who place prior to death of spouse within 6 months of placement.</p>
	<p>Repeated measures ANOVA (care transition between subjects and follow-up point as within subjects) to examine depression.</p>	<p>Time 1 – Time 2 Depression outcomes Non carers and continued carers report stable depression symptoms Carers who placed spouse in care and then experience death of spouse (Home Placement Death) report a significant increase in depression symptoms following placement.</p>	<p>Authors note limitations of small sample size of carer sub-groups and lack of consideration given to other factors which may impact upon the carers experience (social support, financial situation, health of carer and coping methods, meaning given to transition).</p>
Kramer (2000)	<p>Analyses repeated with covariates: spouse's CDR and length of caring at baseline</p> <p>N = 74 100% males Follow up N = 57 (77%) Living with spouse = 43 (58%) Placed in care = 14 (19%) Bereaved = 7 (9%) Lost = 10 (14%)</p> <p>Follow up Series of 2*2 repeated ANOVA and (time*placement status) for each stressor, stress appraisal, CES-D with univariate tests for further analyses</p>	<p>Dementia severity (as measured by the Clinical Dementia Scale) and length of care at baseline were not significant covariates.</p> <p>Baseline: Sample of husbands caring for their wives at home were compared on baseline measures by subsequent transition as well as within carer group comparisons.</p> <p>Time 1 to Time 2 comparisons Husbands who placed wives in care home by time 2 report greater spousal impairment at time 1 baseline interview (independent activities of daily living and memory and behavioural problems) than husbands who do not place wives by time 2.</p> <p>Depression scores Time 1 – Time 2 No significant changes in depression scores* as measured by the CES-D in all carers although scores were above clinical cut-off for depression at time 2 for carers who placed their spouse in care.</p> <p>Carers who continue to care for spouse at home remained below clinical cut-off at time 2 (13.65 time 1 - 12.40, time 2, SD=?) Carers who placed their spouse in care increased to above clinical cut-off at time 2 (15.86 time 1 - 17.36 time 2, SD=?).</p> <p>Carer sub-groups: a third of husbands who continued to care at home and a half of husbands who placed spouses were above the</p>	<p>Pattern of adaptation over time for husbands who continued to care for wives at home (appraised functional limitations of spouses as less stressful and reported lower levels of depression over time).</p> <p>Given small sample size, trend level effects should be interpreted with caution.</p> <p>Husbands who placed wives report no statistically significant increase in depression scores although time 2 above clinical cut-off (*small number of placement cases (n=14) meant insufficient power to detect an effect).</p> <p>Author notes improvements in social resources following placement, anticipation of bereavement before and after transition to nursing home and loss through transition following crises.</p> <p>Non-representative and small sample is noted as a limitation (likely failure to detect meaningful differences) and lack of pre-caregiving data, e.g. depression scores. Short follow-up time frame also limits examination of pattern of adaptation and over-reliance upon self-report data in the absence of objective measures limits understanding. Calls for further prospective, multi-wave longitudinal self-report and objectively measured data.</p>

cut-off indicating risk of depression (two to four times the rate reported in the older adult population). Pre-care depression ratings were not available for carers. Satisfaction with social and recreational activities improved for husbands who placed wives and was stable for those who continued to care at home.

Perceived spousal dependency increased for both groups of carers (continued and placed spouse in care). Increase in personal care activities was greater for husbands who placed wives in care at time 2. Decrease in perceived stress related to memory and behavioural problems was greatest for husbands who placed wives in nursing home although decline also noted in husbands who continue to care at home at time 2.

Mausbach (2007) N = 126 70% Female
Follow up N=ns
Placed in care N=29 (23%)
Bereaved N=19 (15%)
Random regression (mixed effects) models to evaluate change over time regarding placement and depressive symptoms (age at baseline and gender as covariates)

Time1 to time2 – estimated trajectories

No significant change in overload over time for carers who continue to care at home (Pearlin Role Overload Scale).

Depression following transition – estimated trajectories

Significant drop in depression (Hamilton Depression Rating Scale) in the 6 months (no SD) after placement although depression scores not reported in the study.

Overload following transition - estimated

Significant drop in overload in the 6 – 8 months (no SDs) after placement in care although stable over time thereafter.

Females report greater overload and depression scores and lower mastery than males over time.

Carers experience significant improvement in psychological outcomes following placement in care which authors argue is sustained over the time-frame examined (24 months).

Results suggest a temporal relationship between depression, overload and transition.

Numbers of spouses experiencing the transition are small for statistical analyses conducted and authors highlight the need for replication with a larger sample over a longer time frame.

It is unknown whether psychological distress continue to stabilise over time for those who experience transition in care.

Pruchno (1990) N = 315 68% Female
Follow up N=220 (70%)
Living with spouse N=152 (48%)
Placed in care N=68 (22%)

Baseline: Carers considering placement at time1 were older than carers not considering placement and reported greater: spouse forgetfulness; assistance of spouse with daily living; use of services; use of medication to manage their own mood and sleep

The best predictor is 'desire' to institutionalise. Relatively poor prediction of placement in care suggests the need to consider other variables to better explain this transition, for example, the meaning given to the carer role and to placement, the role of sudden change in functioning of either spouse and the role of social support. Placing a spouse in care is helpfully examined as

Bereaved N=23 (7%) Lost N=72 (23%)		Time 1 to Time 2: lost to follow-up Carers who were lost at follow-up were older than carers who participated at follow-up.	a process spanning years rather than an event.
Bivariate correlations and regressions		Time 1 to Time 2: depression scores (CES-D) Carers who placed their spouse by time 2 reported significantly higher depression scores at baseline than carers who continue to care at home (as measured by the CES-D) and these scores were above cut-off (20.16, SD=?) for clinical depression at baseline. Carers who continued to care for their spouse report depression scores below clinical cut-off (14.93, SD=?) at baseline	Carers who no longer derive positive value from caring are more likely to place spouse in care. Unsatisfying relationship combined with physical demands of care, dependent spouse and knowledge of alternatives may predispose carer to consider placement.
Logistic regression tested model of predictors of institutionalisation		Time 1 to Time 2: burden and uplifts Carers who placed their spouse by time 2 reported greater: burden; use of services, use of medication to manage their mood or sleep; desire to place spouse; spouse forgetfulness; asocial behaviours and fewer uplifts (such as embraces with spouse, enjoyment, companionship, spouse gratitude) than those who continued to care at home. There were no differences in quality ratings of current relationship with spouse (4-point rating: poor/ fair/good/excellent) between continued carers or those who placed.	The authors acknowledge limitations of non-random purposive sampling (limits generalisation of findings and not representing of the population of spousal carers more broadly).
		Predictors of continue to care at home: higher carer satisfaction from caring and in caring relationship for a longer period of time. Predictors of placement: carer reports greater 'desire' to place in care at baseline; more forgetful spouses and fewer uplifts. Equation better predicts continued care at home compared with placement in care.	Authors note that spousal carers in the poorest health are underrepresented in the present sample.
Wright (1994a)	N = 30 80% Female Two factor repeated measure ANOVA (time as repeated measure) Pearson's correlations analysed	Baseline: Carer depression scores are significantly higher than non-carers (no participant scored above the clinical cut-off for depression as measured by Short Zung Interviewer Assisted Depression Scale (SDS). Spouses were at 'early to middle stages' of dementia at baseline (as measured by Mini Mental State Examination (MMSE) and Global Deterioration Scale (GDS)).	*Depression scores do not change over time for cares who continue to care at home and carers who place spouse in care home although small numbers mean that there is no statistical power to detect changes. MMSE and GDS scores of spouses with dementia in different transition groups are not significantly different at baseline. There is no measurement of change in MMSE and GDS over time to assess severity of dementia over time. Alzheimer's disease may have progressed at different rates over the course

	relationship between variables at time 1 and time 2	<p>Time 1 – Time 2: Depression symptoms</p> <p>There was no statistical change in depression scores over time for all participants (carers and non-carers therefore the significant difference between these two groups remained over time*)</p>	<p>of the two year follow-up and affected outcomes and a range of life events occurring over this time that were not assessed.</p> <p>Authors recommend further longitudinal research with larger samples and more frequent testing over time.</p>
Wright (1994b) Sample used in Wright (1994a), above	<p>N=30 80% Females Follow up N = 27 (90%) Living with spouse N=12 (40%) Placed in care N=7 (23%) Bereaved N=8 (27%) Lost N=3 (10%)</p> <p>Discriminant analysis Wilks Lambda and univariate F-ratios tested for groups differences in demographic, marital relationship and social interaction variables</p> <p>Non parametric Kruskal-Wallis also tested for group differences</p>	<p>Baseline: All carers scored below clinical cut-off for all carers as measured by Short Zung Interviewer Assisted Depression Scale (SDS).</p> <p>Time 1 to Time 2: Interaction and marital happiness</p> <p>Spouses who continue to care at home report greater marital happiness, positive spousal interactions, commitment to the future and fewer years as a carer characterise compared with those who place spouse in care.</p> <p>There was no difference between carers at different stages of transition on past marital happiness, current affection and tension and no difference in care recipient MMSE and Global Deterioration Scale stages of transition.</p> <p>Placement in care is predicted by low present marital happiness and low commitment to the future of the spousal relationship.. Continued care at home is better predicted than placement.</p>	<p>Predictors of spouse remaining at home: continued commitment to the relationship, positive interaction between spouses and shorter time in carer role. Past marital happiness was not predictive of care status outcome. The author suggests that time since symptom onset may represent impairment or that energy is depleted amongst carers who have been in the role longer.</p> <p>The author acknowledges the limitations of the small sample size (limits inferences drawn from statistical tests) and of the non-random purposive sampling (limits generalisation of findings). Longer follow-up periods with more frequent interview are appropriate to improve understanding of the dynamic nature of the spousal relationship and the marital interactions involved in maintenance, decline and mortality.</p>
Zarit (1986)	<p>N = 64 52% Female Follow up N=58 (91%) Living with N=32 (50%) Placed in care N=11 (23%) Bereaved N=15 (17%) Lost N=6 (9%)</p> <p>Baseline: t-tests compared baseline characteristics of carers who placed spouses and those</p>	<p>Baseline: carers who placed spouse in care had higher initial burden scores. Females report higher burden scores than males.</p> <p>Time 1 – Time 2: Memory and behavioural problems</p> <p>The total frequency of memory and behavioural problems remained the same time 1 compared to time 2. Memory and behaviour problems as scored by carers and as rated by clinician administered Mental Status Questionnaire did not differ between carers who placed in care and carers who continued to live at home with their spouse.</p>	<p>Carers' perception of burden are associated with nursing home placement. Carer appraisal of care task requirements is important in determining the level of perceived burden. Carers vary in their problem solving ability and react differently to spouse behaviours.</p> <p>Severity of care recipient symptoms did not predict care home placement although behaviours such as care recipient inability to undertake personal care were associated with placement.</p> <p>Spouses report low levels of social support and a need for respite care</p>

who continued to care at home	Care recipients who were less able to undertake personal care were more likely to be placed within the following two years. All carers reported more deficits in activities of daily living were reported at follow-up although some problematic behaviours were perceived to lessen by time 2.	which they had been unable to obtain. A small number of carers report minimal social support after care placement which demonstrates a risk of isolation and lack of support following care placement. Authors note the limitations of small numbers in different care transitions groups on statistical analyses.
Zero-order correlations examined burden and carer variables at time 2.		
Paired t-tests examined changes in carer scores time1 to time2	<p>Time 1 – Time 2: Burden and social support</p> <p>Burden differences between males and females at baseline were not apparent at follow-up. Burden scores decreased significantly at time 2 for continued carers and those who placed their spouse in care. All carers reported relatively low levels of social support and greater tolerance for their spouses memory and behaviour problems at time 2. Availability of social support did not impact upon placement decision although authors note the limited statistical power due to small numbers in transition groups. There was no difference in baseline ratings of quality of marital relationship prior to onset of dementia (10-point rating: poor – excellent) between continued carers and those who placed their spouse in care homes.</p>	<p>Authors argue that the study findings emphasise the adaptive nature of caring over time for a spouse with dementia and that carers' ability to tolerate behaviour increased over time may be due to learning to manage problems and reappraising the care situation.</p> <p>The challenges of caring for a spouse with dementia change with time although change does not necessarily represent an increase in difficulty.</p>

1.6 Methodological limitations of studies included in the review

The studies included in this review are characterised by a wide range of carer and care recipient measures, of variable quality and of limited comparability, that are applied across different time scales and inconsistently reported. This diversity inhibits meaningful comparison within and between studies of the impact of caring for a spouse with dementia on psychological well-being over time. These are discussed in more detail below.

1.6.1 Sampling

Four studies noted issues of recruitment selection bias because the common method of sourcing through Alzheimer's Associations and support groups excludes those not engaged and is not representative of carers more generally (Kramer, 2000; Pruchno *et al.*, 1990; Wright, 1994a; Bond *et al.*, 2003). There is disagreement as to whether this method of carer recruitment over-inflates rates of psychological distress because those in attendance may be in greater need of support (Schultz & Williamson, 1994) or underestimates problems because more impaired carers are unable to attend support groups (Dura *et al.*, 1990). In this review, Pruchno *et al.*, (1990) comment explicitly that their method of recruitment under-represents those carers who are in poorer health (Table 7: Conclusions, p. 40).

1.6.2 Outcome measures and follow-up

Studies were characterised by relatively short follow-up (one or two years) and it was not possible to examine, with certainty, the impact of care transition on carer well-being over comparable time frames because of variation in conducting and reporting of timing of follow-up studies and absence of reports of time elapsed since transition in three studies (Pruchno *et al.*, 1990; Wright, 1994a; 1994b; Zarit *et al.*, 1986). A number of authors called for longer prospective cohort studies with regular re-interview because one-off or short-term follow-up precluded thorough examination of the pattern of adaptation that may occur during the course of spousal caring (Bond & Clark, 2002; Grant *et al.*, 2002; Wright, 1994b).

Limited assessment of positive aspects of spousal dementia care restricted the findings of carer emotional well-being to the absence of negative care outcomes such as depression, burden and stress which were assessed using different scales thereby restricting the potential for meaningful comparisons and definitive conclusions.

It was not possible to examine the impact of stage of dementia on carer well-being because only three studies reported on dementia severity scores taken at baseline rather than at follow-up (Bond *et al.*, 2003; Wright, 1994b; Zarit *et al.*, 1986). In addition, only two studies compared physical well-being between different carer groups using different measures at both baseline and follow-up (Bond *et al.*, 2003; Kramer, 2000).

1.6.3 Relationship features

Seven studies included in this review gave no consideration to past or present quality of the spousal relationship despite the importance of current marital happiness and spousal interaction in predicting continued care at home (Wright, 1994b). Only two studies examined quality of marital relationship using different rating scales and time frames (current and past, Pruchno *et al.*, 1990; Zarit *et al.*, 1986, respectively). Authors of four studies acknowledged the need to examine the meaning and commitment associated with the care role (Bond *et al.*, 2003; Pruchno *et al.*, 1990; Grant *et al.*, 2002; Wright, 1994a).

1.6.4 Small sample size following transition

Reduced power in statistical analysis due to small sample size is noted by authors in five studies in this review (Grant *et al.*, 2002; Kramer, 2000; Mausbach *et al.*, 2007; Wright, 1994b; Zarit *et al.*, 1986, Table 7: Conclusions). This impeded comparison of basic demographics and examination of depression symptoms following care home transition (Kramer, 2000; Wright, 1994a).

1.6.5 Dementia severity and diagnosis

As outlined in section 1.5.4.8, p. 18, study samples varied in regard to dementia diagnosis mix although the majority of carers were looking after spouses with Alzheimer's Disease. Although this is the most commonly diagnosed dementia, this limits the generalisability of findings. It is acknowledged that frontotemporal dementias may impact more severely upon carers (Nunnemann *et al.*, 2012) with a greater proportion reporting depression than carers of individuals diagnosed with Alzheimer's Disease (Mioshi *et al.*, 2009; Kaiser & Panegyres, 2006).

1.7 Discussion

1.7.1 Summary of results

This review summarises and evaluates evidence from published longitudinal studies to assess whether there are differences in emotional well-being between carers and non-carers over time and examine the impact of care transition on the emotional well-being of spousal dementia carers. The review findings are summarised and discussed in more detail below and followed by a consideration of review limitations, clinical implications and research recommendations. Results uncovered by the review are described in Table 7.

1.7.2 Review Question 1: Is the emotional well-being of dementia carer spouses different to non-carer spouses over time?

This review demonstrates that spousal carers experience poorer emotional well-being than non-carers in regards to higher levels of perceived and environmental stress over time (Clark *et al.*, 2007, section 1.5.6.3, p.32) and higher symptoms of depression at baseline (Grant *et al.*, 2002; Wright, 1994a, section 1.5.6.2, p.31). The finding that spousal carers experience poorer emotional well-being over time compared with spousal non-carers (Clark *et al.*, 2007; Grant *et al.*, 2002; Wright, 1994a) is consistent with meta-analyses of dementia carers

(Pinquart & Sorensen, 2011; Vitaliano *et al.*, 2003; 2005), systematic review (Cuijpers, 2005) and cross-sectional research comparing spousal carers with non-carers (Adams, 2008; Mills *et al.*, 2009).

However, there are a range of factors other than carer status that may account for differences in stress and depression levels between carers and non-carer spouses and consideration must be given to how well matched the comparisons groups were. Non-carer comparison spouses did not differ statistically in gender, age and marital status in the three studies although one study found that length of marriage was shorter in carer spouses compared to non-carer spouses due to second and third marriages. No statistical difference was found in measures of physical well-being between carers and non-carers at baseline in two studies although socioeconomic status and education levels were found to be “slightly higher” in non-carers in one study, similar in another study and not assessed in a third study (section 1.5.6.1, p.31). In addition, the absence of pre-care measures in studies included in the present review, means that causality cannot be attributed.

1.7.3 Review Question 2: is the emotional well-being of spousal dementia carers shaped by care transition?

1.7.3.1 Carers who continue to look after their spouse at home

This review discovered evidence of stability in well-being in carers who continue to live with their spouses at follow-up:

1. Stable levels of depression (Bond *et al.*, 2003; Kramer, 2000; Grant *et al.*, 2002; Wright 1994a, section 1.5.7.1, p.32), perceived stress (Clark *et al.*, 2007) and reduced burden (Zarit *et al.*, 1986) were found in carers who continued to care for their spouses at home, section 1.5.7.2, p.32.

2. Higher number of care uplifts (Pruchno *et al.*, 1990) and greater marital happiness and positive spousal interactions (Wright, 1994b) reported at baseline were associated with continued care at home, section 1.5.8.4, p. 35.

Stable levels of depression and decreased perception of burden and stress in carers who continue to live with their spouse at home found in this review suggest a degree of carer adaptation over time. These findings are consistent with studies that highlight the benefits of training and support intervention in managing emotional distress in dementia carers (Elvish *et al.*, 2013; Gallagher-Thompson & Coon, 2007) and in delaying care home placement in spousal dementia carers (Mittelman *et al.*, 2006).

It is possible, however, that longitudinal study results underestimate negative impacts of care over time if carers with poorer outcomes, for example, higher depression and stress, are less likely to be recruited and more likely to disengage from longitudinal studies due to competing demands. Results from two studies in the present review that compared drop-outs with continued participants (Pruchno *et al.*, 1990; Bond & Clark, 2002) suggest that healthier, younger carers remain engaged in longitudinal studies while older carers are more likely to drop out of longitudinal research.

The study with the highest attrition rate (Mausbach *et al.*, 2007) reported the most positive psychological carer outcomes following transition relative to other studies in the review as evidenced by lower depression and overload. This may be because the most depressed and stressed carers disengage from the study or it may be because carers feel less depressed and overloaded following transition. It could be argued that this systematic review summarises and evaluates findings on spousal carers who are well enough to participate in long term research although it is not possible to address this point definitively because six studies failed to examine non-participation demographics.

It is noteworthy that only two studies in the present review (Section 1.7.3.1, finding 2) examined positive aspects of care, reflecting the tendency of research to focus on the negative aspects of dementia care at the cost of learning from positive, sustainable aspects of care. Both studies suggest that positive experiences in spousal care may be protective in enabling continued care at home and are worthy of further study.

Positive adaptation through adversity, posttraumatic growth (Tedeschi & Calhoun, 1996), has been examined empirically in familial carers of chronic health conditions such as cancer (Kim *et al.*, 2008) and multiple sclerosis (Pakenham, 2005), although not in dementia carers. Assessing positive growth may contribute to understanding this population more fully and encourage the use of a positive conceptual framework to understand the experience of dementia carers. This may facilitate greater understanding of positive components of care and contribute to carer intervention programmes (Carbonneau *et al.*, 2010).

1.7.3.2 Carers who experience the transition of their spouse to permanent placement in care home

This review found inconsistent evidence on the impact of care home placement on spousal carer well-being:

1. Emotional well-being of carers who placed spouses by follow-up was significantly lower at baseline than spouses who continued to care at home, as evidenced in three studies through lower social activities (Bond *et al.*, 2003, section 1.5.7.6, p.33), greater burden (Pruchno *et al.*, 1990; Zarit *et al.*, 1986, section 1.5.7.5, p.33), and higher levels of depression (Bond & Clark, 2002; Pruchno *et al.*, 1990, section 1.5.7.4, p.33).
2. Two studies found lower emotional well-being in carers who placed spouses at follow-up as evidenced by higher depression after placement and before the death of spouse within six months of placement (Grant *et al.*, 2002, section 1.5.7.4, p.33.)

and significantly higher environmental stress levels (Clark, *et al.*, 2007), section 1.5.7.5, p.33.

3. Improvements in emotional well-being were found following care home placement in five studies as evidenced by significant reductions in depression symptoms (Mausbach *et al.*, 2007, section 1.5.7.4, p.33), burden (Zarit *et al.*, 1986), perceived stress levels (Clark *et al.*, 2007) and overload (Mausbach *et al.*, 2007) (section 1.5.7.5, p. 33), and increases in social activities (Bond *et al.*, 2003) and in husband's satisfaction with social activities (Kramer, 2000), section 1.5.7.6, p. 33 - 34.
4. Carers who placed spouses in care reported symptoms of depression above clinical cut-off in four articles (Bond & Clark, 2002; Bond *et al.*, 2003; Kramer, 2000; Pruchno *et al.*, 1990) and below clinical cut-off in two articles (Grant *et al.*, 2002; Wright, 1994a). Sub-groups of carers at risk of depression were identified in Kramer (2000) and Grant *et al.*, (2002), section 1.5.7.4, p.33.
5. Dementia severity was associated with care home placement in one study (Bond *et al.*, 2003) and not in two studies (Wright, 1994b; Zarit *et al.*, 1986). It was not possible to comment definitively on the impact of care recipient impairment on carer well-being, section 1.5.8.2, pp. 34 - 35.

In the present review, emotional well-being of spousal dementia carers varied, with particular groups of spousal carers at heightened risk of, for example, depression compared to other groups of carers. This includes the period of time before (at baseline) and after placing spouse in a care home (Bond & Clark, 2002; Kramer, 2000; Pruchno *et al.*, 1990). The results of the present review suggest that the period before care home placement may be particularly challenging emotionally for carers who place their spouse in care, as evidenced by heightened burden, depression and lower social activity at baseline compared to carers who continue to live with their spouse (Section 1.7.3.2, finding 1). In addition, the period after placement and before the death of spouse within six months of placement may be

emotionally challenging for carers with greater depression and stress (Section 1.7.3.2: finding 2). Furthermore, improvements in emotional well-being may follow care home placement as evidenced by significant reductions in depression, perceived stress levels, overload, burden and increases in social activities and in husband's satisfaction with social activities (Section 1.7.3.2: finding 3).

Mixed results relating to care home placement may be understood alongside published literature. Care home placement is associated with depression, burden and emotional exhaustion in spousal dementia carers (Ablitt *et al.*, 2009; Gaugler *et al.*, 2010; Schulz *et al.*, 2004) and with ambivalent emotional responses (Lundh *et al.*, 2000), including relief, despair (Mullin *et al.*, 2011) and guilt which may continue beyond the time of placement (Hennings *et al.*, 2013). Emotional distress in spousal carers is also associated with lack of perceived support relating to the decision to place in care (Nolan & Dellasega, 2000) and carer concerns about the quality of care provided in care homes (Davies & Nolan, 2006; Train *et al.*, 2005).

In the present review, examining emotional well-being at baseline whilst carers are living with their spouses showed that some carers experience poorer well-being in the year prior to care home placement. This suggests that there is a need to conceptualise care home placement as an integral part of the care process which merits attention while care is being provided at home. Examining well-being after care home placement in the present review showed that some carers experience an increase in well-being whilst others experience a decrease in well-being. These findings suggests that care professionals may need to be vigilant in monitoring emotional well-being before and after care home placement and supporting carers to maintain continuity of care for their spouse with dementia where this is desired.

1.7.4 Inconsistent results and methodological issues

Review findings were inconsistent and seem hard to reconcile because of a number of methodological issues pertaining to the studies in this review including the use of different age ranges and gender proportions, different scales to assess stress, depression and burden across different time frames and lack of assessment of stage or severity of dementia between baseline and follow-up. The relationship between care recipient well-being and spousal well-being is complex with both severity of behavioural problems and rate of change in care recipient functioning associated with carer well-being over time (Perren *et al.*, 2006). It is important to consider that carers are looking after their spouse at different stages of dementia and it is possible that dementia severity is lower in those cases where carers continue to live with their spouse compared to cases where carers place their spouse in a care home.

Studies in the present review examined stage of dementia in a limited way. Only three studies reported on the association between dementia severity and care placement with mixed results (one study found a significant association between dementia severity and care home placement and two studies found no association between dementia severity and placement, Section 1.7.3.2: finding 5).

Not all dementia carers are equal in terms of distress tolerance and resources, for example, input received from other support services may impact upon carer outcomes (Knight *et al.*, 1993) although studies included in the review did not assess such input. Differences in carer well-being outcomes have been understood more generally in the context of stress, appraisal, coping (Folkman & Lazarus, 1980; Folkman *et al.*, 1986; Lazarus & Folkman, 1984) and adaptation (Pearlin *et al.*, 1990). Coping refers to behavioural and psychological attempts to manage stressful situations (Folkman & Lazarus, 1988) which some carers manage better than others (Cooper *et al.*, 2008; McLennon *et al.*, 2011) although coping has been poorly

researched in dementia carers as demonstrated by systematic review and meta-analysis (Li *et al.*, 2012).

Poor physical health in spousal dementia carers is associated with care home placement (Kiecolt-Glaser *et al.*, 1991; Von Kanel *et al.*, 2012) and may impact upon the emotional well-being of carers who place spouses in permanent care. Only two studies included in the review compared physical health of carers who placed their spouse and those who continued to live with their spouse at baseline and follow-up. Both studies found no difference at baseline between these two groups of carers and improvement in perceived change in health in carers who placed their spouse at follow-up although one study found no difference in physical health scores at follow-up between the carer groups, section 1.5.8.1, p. 34). We acknowledge that physical health is implicated in care transition although it was not possible in the present review to separate out the impact that physical health and dementia severity had upon carer well-being.

1.7.5 Review limitations

This systematic review is limited by the search strategy employed which covered articles published only in English and searched particular databases. Due to the elevated risk of retrieval bias, authors were contacted about additional published and unpublished research to ascertain whether there were further relevant publications in other languages or in other databases not uncovered by the literature search although no further papers were uncovered. The review relied upon studies which were dated, with research in three studies conducted almost twenty five years (Pruchno *et al.*, 1990; Wright, 1994a; Zarit *et al.*, 1986) and over a decade ago in three studies (Kramer, 2000; Grant *et al.*, 2002; Bond & Clark, 2002). The findings of these studies may, therefore, demonstrate age-cohort effects including gender specific role focus (Zarit *et al.*, 1986) and cohort related attitudes to marital commitment (Wright, 1994b) that may not exist in current or future spousal carers.

The lack of good quality up to date studies in this population is an important finding and the majority of studies were from the US and two from Australia. Both countries are culturally different from the UK with different systems of health and social care funding. Results from studies conducted in these countries may not generalise to the UK and have limited validity in informing the UK or European carer evidence base. No UK/European studies were uncovered in the literature search which limits the potential impact for research to shape practice at a clinical and policy level and demonstrates a need for high quality prospective spousal dementia carer cohort studies using comparable methods and times frames.

While the specific focus of this review is upon spousal carers because of the unique set of emotional and relationship challenges presented in caring for a spouse with dementia, we acknowledge that other carers such as adult child carers play a vital role in supporting individuals with dementia and are worthy of research attention. It is hoped that future longitudinal prospective cohort studies address some of the methodological weaknesses identified in this review and progress the carer evidence base by studying different sub-groups of carers over time with separate analyses for spousal, adult child and other familial carers.

1.7.6 Clinical Implications

Dementia carers have a vital role in looking after their spouse with dementia and in shaping person centred care for their spouse and require support to maintain their own psychological and physical health not least to be enabled to provide care over time and to be supported through care transitions. Despite limitations, this review has drawn together seemingly disparate and inconsistent findings to inform clinical practice.

- Poorer emotional well-being amongst carers compared with non-carers may highlight the need for basic primary health care health screening in this population over time that may usefully include symptoms of depression and stress examined

using standardised and validated measures for older adults to enable timely intervention, where appropriate.

- Examining emotional well-being, including perception of social support and positive aspects of the care role, for example, as part of psychosocial screening for carers, may identify carers who are at heightened risk of depression and stress and facilitate support and timely psychological intervention.
- Care professionals involved in care transition and working in care homes may have a role in identifying carers at risk of depression and stress.
- The transition to permanent care home placement is associated with heightened depression, particularly if spouses die within six months of placement. Blanket post-diagnostic support of one year is unlikely to meet the emotional needs of spousal carers which may span over years.

1.7.7 Research recommendations

The experience of dementia varies for each individual and carer, indeed spousal dementia carers are a diverse group who merit further research over longer periods of time. Multi-wave prospective cohort studies that employ qualitative and quantitative methods using standardised and validated carer and care recipient measures with regular tracking should be used to examine the care experience including meaning given to care, placement and loss alongside the factors associated with spousal dementia care such as depression and stress and positive aspects of care. Given the complex array of emotions experienced in caring for a partner with dementia and associated with care home placement, it will be worthwhile for future studies to examine the experience of emotions and how these are managed. It will be of use to identify sub-groups of carers who may be at risk of low emotional well-being and examine factors which support care at home for as long as is beneficial and appropriate for both spouses.

1.8 Conclusions

This review found that the available evidence base is restricted to a small number of low to medium quality longitudinal studies conducted over relatively short time frames in the US and Australia whose findings may not generalise to other countries. Due to methodological limitations, current longitudinal studies are unable to definitively conclude on the impact of care placement on emotional well-being of spousal carers over time and further analysis and exploration of the impact of care transition on carer emotional well-being is required.

There is a need to support the emotional well-being of spousal dementia carers at all stages in the care process and especially around transition to care home. It is challenging to identify and account for the range of variables that impact upon the care experience and we have much to learn from carers who continue to care for their spouse at home as well as from those who continue to care following permanent placement. There are sub-groups of carers who may experience poor emotional well-being during the course of care as well as positive adaption in their care role. More work is required on identifying and uncovering factors which may help predict and support these carers.

Conflict of interest

None

Description of author roles

Roisin Ash conceived the idea, designed the review, searched the literature, reviewed papers and wrote the paper. Professor Ken Laidlaw provided academic supervision and comments on drafts of the paper.

Acknowledgements

I would like to thank Dr Jason Godfrey, Dr John Logie, Dr James Carnie and Dr Paul Millar for taking on the role of second assessors for papers included in this article.

1.9 References

- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, 13, 497–511.
- Adams, K. B., McClendon, M. J., & Smyth, K. A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7, 301–319.
- Akpinar, B., Kucukguc, O., & Yener, G. (2011). Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship*, 43, 248–254.
- Amico, K. R. (2009). Percent Total Attrition: A poor metric for study rigor in hosted intervention designs. *American Journal of Public Health*, 99, 1567–1575.
- Ankri, J., Andrieu, S., Beaufils, B., Grand, A., Henrard, J. C. (2005). Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. *International Journal of Geriatric Psychiatry*, 20, 254–260.
- Arean, P. A., Miranda, J. (1997). The utility of the Center for Epidemiological Studies: Depression Scale in older primary care patients. *Aging & Mental Health*, 147–156.
- Barusch, A. S., & Spaid, W. M. (1989). Gender differences in caregiving: why do wives report greater burden? *The Gerontologist*, 29, 667–676.
- Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging*, 15, 259–271.
- Black, W. & Almeida, O. P. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, 16, 295–315.
- Bond, M.J., & Clark, M.S. (2002). Predictors of the decision to yield care of a person with dementia. *Australasian Journal on Ageing*, 21, 86–91.

- Bond, M. J., Clark, M. S., & Davies, S. (2003). The quality of life of spouse dementia caregivers: Changes associated with yielding to formal care and widowhood. *Social Science and Medicine*, 57, 2385–2395.
- Boss, P. (2011). *Loving someone who has dementia: how to find hope while coping with stress and grief*. United States of America. Jossey-Bass.
- Braun, M., Bailey, B., Perren, S., Hornunga, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective *Aging & Mental Health*, 13, 426–436.
- Brink, T. L., Yesavage, J. A., Lum, O., Heersema, P., Adey, M. (1982). Screening tests for geriatric depression. *Clinical Gerontologist*, 1, 37–44.
- Brown-Wilson, C., & Davies, S. (2009). Providing quality care: Developing relationships in long term care environments: the contribution of staff. *Journal of Clinical Nursing*, 18, 1746–1755.
- Burns, A., Lawlor, B., & Craig, S. (2002). Rating scales in old age psychiatry. *British Journal of Psychiatry*, 180, 161–167.
- Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in Dementia. *Dementia*, 9, 327–353.
- Chenoworth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist*, 26, 267–272.
- Clark, M. S., Bond, M. J. (1995). The Adelaide Activities Profile: a measure of lifestyle activities of the elderly. *Aging: Clinical and Experimental Research*, 7, 174–184.
- Clark, M. S., Bond, M. J. (2000). The effect on lifestyle activities of caring for a person with dementia. *Psychology, Health & Medicine*, 5, 13–27.
- Clark, M. S., Bond, M. J., & Hecker, J. R. (2007). Environmental stress, psychological stress and allostatic load. *Psychology Health & Medicine*, 12, 18–30.

Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 386–396.

Cooper, C., Katona, C., Orrell, M., Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929–936.

Croog, S. H., Burleson, J. A., Sudilovsky, A., Baume, R. M (2006). Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging & Mental Health*, 10, 87–100.

Cuijpers, (2005). Depressive disorders in caregivers of dementia patients: A systematic Review. *Aging & Mental Health*, 9, 325–330.

Davies, S., & Nolan, M. (2006). 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies*, 43, 281–291.

Dougall, A. L. & Baum, A. (2012). Stress, health and illness. In A. Baum, A. A. Tracey, J. S. Revenson (Eds.) *Handbook of Health Psychology* (2nd Edition, pp. 53–78). Taylor & Francis Group.

Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five years effects of structured intervention for caregivers of spouse with Alzheimer's disease. *Social Science and Medicine*, 63, 957–967.

Dura, J. R., Haywood-Niler, E., & Kiecolt-Glaser, J. K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's Disease dementia: A preliminary comparison. *The Gerontologist*, 30, 332–336.

Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research: Linking research with practice*, 13, 106–125.

- Epstein-Lubow, G., Davis, J. D., Miller, I. W., & Tremont, G. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, 21, 198–203.
- Fengler, A. P., & Goodrich, N. (1979). Wives of Elderly Disabled Men: The Hidden Patients. *The Gerontologist*, 19, 175–183.
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P. R., Rimmer, E., & Scazufca, M. (2006). Global prevalence of dementia: a Delphi consensus study. *The Lancet*, 366, 9503, 2112–2117.
- Finch, J. (1995). Responsibilities, obligations and commitments. In I. Allen & E. Perkins (Eds.) *The future of family care for older people*. London: HMSO.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219–239.
- Folkman, S., & Lazarus, R. S. (1984). Coping and adaptation. In W. D. Gentry (Ed.) *The handbook of behavioral medicine* (pp. 282–325). New York: Guilford.
- Folkman, S., & Lazarus, R. S. (1986). Stress processes and depressive symptomatology. *Journal of Abnormal Psychology*, 95, 107–113.
- Folkman, S., & Lazarus, R. S. (1988). Coping as a Mediator of Emotion. *Journal of Personality and Social Psychology*, 54, 466–475.
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-Based Psychological Treatments for Distress in Family Caregivers of Older Adults. *Psychology and Aging*, 22, 37–51.
- Gallichio, L., Siddiqi, N., Landenberg, P., Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, 17, 154–163.

- Gaugler, J. E., Davey, A., Pearlin, L. I., & Zarit, S. H. (2000). Modeling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging*, 15, 437–450.
- Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003a). Predicting institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, 43, 219–229.
- Gaugler, J.E., Pot, A.M., & Zarit, S.H. (2007). Long-term adaptation to institutionalization in dementia caregivers. *The Gerontologist*, 47, 730–740.
- Gaugler, J.E., Roth, D.L., Hayley, W. E., & Mittelman, M. S. (2008). Can Counseling and Support Reduce Burden and Depressive Symptoms in Caregivers of People with Alzheimer's Disease During the Transition to Institutionalization? Results from the New York University Caregiver Intervention Study. *Journal of the American Geriatric Society*, 56, 421–428.
- Gaugler, J.E., Roth, D.L., Hayley, W. E., & Mittelman, M. S. (2011). Modelling trajectories and transitions: results from the New York University caregiver intervention. *Nursing Research*, 60, S28–S37.
- Gaugler, J. E., Yu, F., Krichbaum, K., Wyman, J. F. (2009a). Predictors of Nursing Home Admission for Persons with Dementia. *Medical Care*, 47, 191–198.
- Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2009b). Predictors of Change in Caregiver Burden and Depressive Symptoms Following Nursing Home Admission. *Psychology and Aging*, 24, 385–396.
- Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine*, 8:85.
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003b). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging*, 18, 171–180.

- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253–259.
- Gilhooley, M. L. M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology*, 57, 35–44.
- Gonzalez, E. W., Polansky, M., Lippa, C. F., Walker, D., & Feng, D. (2011). Family Caregivers At Risk: Who Are They? *Issues in Mental Health Nursing*, 32, 528–536.
- Goy, E., Freeman, M., & Kansagara, D. (2010). A systematic evidence review of interventions for non-professional caregivers of individuals with dementia. Department of Veterans Affairs Health Services Research & Development Services. VA-ESP Project #05-225.
- Grant, I., Adler, K. A., Patterson, T. L., Dimsdale, J. E., Ziegler, M. G., & Irwin, M. R. (2002). Health consequences of Alzheimer's caregiving transitions: Effects of placement and bereavement. *Psychosomatic Medicine*, 64, 477–486.
- Hamilton, M. (1960). A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry*, 23, 56–62.
- Harden, A., Rees, R., Shepherd, J., Brunton, G., Oliver, G., & Oakley, A. (2001). Young people and mental health: a systematic review of research on barriers and facilitators. EPPI Report, September 2001.
- Hazan, C., & Shaver, P. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality and Social Psychology*, 52, 511–524.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the Death of a Loved One and Mental Health in Bereaved Caregivers of Patients with Dementia: Findings from the REACH Study. *Journal of Palliative Medicine*, 9, 683–693.
- Hennings, J., Froggatt, K., & Payne, S. (2013). Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study. *Palliative Medicine*, 0, 1–9.

Hong & Kim, (2008). Family caregiver burden by relationship to care recipient with dementia in Korea. *Geriatric Nursing*, 29, 267–274.

Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., Martin, R. L. (1982). A clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566–578.

Joling, K.J., Hout, H.P.J. van, Schellevis, F.G., Horst, H. E. van der, Scheltens, P., Marwijk, H.W.J. van (2010). Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *American Journal of Geriatric Psychiatry*, 18, 146–153.

Kahn, R. L., Goldfarb, A. I., Pollack, M., Peck, R. (1960). Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry*, 117, 326–328.

Kaiser & Panegyres, (2006). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimers Disease and Other Dementias*, 21, 398–402.

Kim, Y., Carver, C., Deci, E., Kasser, T. (2008). Adult attachment and psychological wellbeing in cancer caregivers: the meditational role of spouses' motives for care giving. *Health Psychology*, 27 (2), 8144–8154.

Kim, Y., & Schulz, R. (2008). Family Caregivers' Strains : Comparative Analysis of Cancer Caregiving With Dementia, Diabetes, and Frail Elderly Caregiving. *Journal of Aging and Health*, 20, 483–503.

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. HTA Initiative 13, Alberta Heritage Foundation for Medical Research.

Knapp, M., & Prince, M. (2007). Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London School of Economics). Alzheimer's Society: London.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33, 240–248.

Knop, D. S., Bergman-Evans, B., & McCabe, B. W. (1998). In sickness and in health: An exploration of the perceived quality of the marital relationship, coping and depression in caregivers of spouses with Alzheimer's disease. *Journal of Psychosocial Nursing and Mental Health Services*, 36, 16-21.

Kramer, B. J. (2000). Husbands caring for wives with dementia: A longitudinal study of continuity and change. *Health and Social Work*, 25, 97–107.

Larson, E. B., Shadlen, M. F., Wang, L., McCormick, W. C., Bowen, J. D., Teri, L & Kukull, W. A. (2004). *Annals of Internal Medicine*, 140, 501–509.

Lazarus, R.S., & Folkman, S. (1974). *Stress, Appraisal and Coping*. New York: Springer.

Lewis, M. L., Hepburn, K., Narayan, S., & Kirk, L. N. (2005). Relationship matters in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias*, 20, 341–347.

Li, R., Cooper, C., Bradley, J., Amanda Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis, *Journal of Affective Disorders*, 139, 1–11.

Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K., & Cooper, C. (2010). Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *British Medical Journal*, 341,c4184, August 18.

Luengo-Fernandez, R., Leal, J., & Gray, A. (2010). *The economic burden of dementia and associated research funding in the United Kingdom*. A report produced by the Health Economics Research Centre, University of Oxford for the Alzheimer's Research Trust.

- Lundh, U., Sandberg, J., Nolan, M. (2000). 'I don't have any other choice': spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32, 1178–1186.
- Luppino, F. S., de Wit, L. M., Bouvy, P. F., Stijnen, T., Cuijpers, P., Penninx, B. W. J. H., & Zitman, F. G. (2010). Overweight, Obesity, and Depression: A Systematic Review and Meta-analysis of Longitudinal Studies. *Archives of General Psychiatry*, 67, 220–229.
- Lutzsky, S. M., & Knight, B. G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9, 513–519.
- Lyness, J. M., Noel, K., Cox, T., King, C., Conwell, D. A., Caine, Y. (1997). Screening for depression in elderly primary care patients. *Archives of Internal Medicine*, 157, 449–454.
- Martin, M., Peter-Wight, M., Braun, M., Hornung, R., & Scholz, U. (2009). The 3-phase-model of dyadic adaptation to dementia: why it might sometimes be better to be worse. *European Journal of Ageing*, 6, 291–301.
- Mausbach, B. T., Aschbacher, K., Patterson, T. L., von Kanel, R., Dimsdale, J. E., Mills, P. J., (2007). Effects of placement and bereavement on psychological well-being and cardiovascular risk in alzheimer's caregivers: A longitudinal analysis. *Journal of Psychosomatic Research*, 62, 439–445.
- McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, 7, 81–91.
- McLennnon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15, 522–530.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498–507.

- Mills, P. J., Ancoli-Israel, S., & Grant, I. (2009). Effects of Gender and Dementia Severity on Alzheimer's Disease Caregivers' Sleep and Biomarkers of Coagulation and Inflammation. *Brain, Behavior and Immunity*, 23, 605–610.
- Mioshi, E., Kipps, C. M., & Hodges, J. R. (2009). Activities of daily living in behavioral variant Frontotemporal Dementia: differences in caregiver and performance-based assessments. *Alzheimer Disease and Associated Disorders*, 23, 70–76.
- Mittelman, M.S., & Epstein, C. (2009). The NYU caregiver intervention, the original study and issues in early translations in diverse community settings, *The Gerontologist*, 49, 387–387.
- Mittelman, M., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67, 1592–1599.
- Montgomery, R. J. V., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs adult children. *Journal of Gerontology*, 49, S62–S74.
- Moore, J. T., Bobula, J. A., Short, T. B., Mischel, M. (1983). A functional dementia scale. *Journal of Family Practice*, 16, 499–503.
- Morrill, E., F., Brewer, N. T., O'Neill, Lillie, S. E., Dees, E. C., Carey, L. A. Rimer, B. K. (2008). The interaction of post-traumatic growth and post-traumatic stress symptoms in predicting depressive symptoms and quality of life. *Psycho-Oncology*, 17, 948–953.
- Morris, R. G., Morris, L. W., & Britton, P. G. (1988). Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British Journal of Psychiatry*, 153, 147–156.
- Motenko, A. K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *The Gerontologist*, 29, 166–172.

- Mui, A. C., Burnette, D., & Mei Chen, L. (2002). Cross cultural assessment of geriatric depression: a review of CES-D and GDS. In J. H. Skinner, J.A. Teresi, D. Holmes, S. M. Stahl, A. L. Stewart,. (Eds.) *Multicultural measurement in older populations* (pp.147–178). Springer publishing company.
- Mullin, J., Simpson, J., & Froggatt, K. (2011). Experiences of spouses of people with dementia in long-term care. *Dementia*, 12, 177–191.
- Mulrow, C. D., Williams, J. W., Gerety, M. B., Ramirez, G. Montiel, O.M., Kerber, C. (1995). Case-finding instruments for depression in primary care settings. *Annals of Internal Medicine*, 122, 913–921.
- Nolan & Dellasega, (2000). 'I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, 31, 759–767.
- Nunnemann S., Last, D., Schuster, T., Förstl, H., Kurz, A., & Diehl-Schmid, J. (2011) Survival in a German population with frontotemporal lobar degeneration. *Neuroepidemiology*, 37, 160–165.
- Ornstein, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. *International Psychogeriatrics*, 24, 1536–1552.
- Ory, M., Yee, J., Tennstedt, S., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In Schulz, R. (Ed.), *Handbook on Dementia Caregiving: Evidence-based interventions for family caregivers*. New York: Springer.
- Pakenham, K. I. (2005). The positive impact of multiple sclerosis (MS) on carers: Associations between carer benefit finding and positive and negative outcomes. *Disability and Rehabilitation*, 27, 985–997.

- Parker, D., Mills, S., & Abbey, J. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence Based Healthcare*, 6, 137–172.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594.
- Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health*, 10, 539–548.
- Pinquart, M., & Sörensen, S. (2003a). Associations of stressors and uplifts of care with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology*, 58, 112 – 128.
- Pinquart, M., & Sörensen, S. (2006a). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology, Psychological Sciences*, 61, 33–45.
- Pinquart, M., & Sörensen, S. (2006b). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18, 577–595.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological and Social Sciences*, 62, 126–137.
- Pinquart, M., & Sörensen, S. (2011). Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults: A Meta-Analytic Comparison. *Psychology and Aging*, 26, 1–14.
- Pruchno, R. A., Michaels, J. E., & Potashnik, S. L. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology: Social Sciences*, 45, 259–266.

- Qualls, S. H. (2008). Caregiver family therapy. In B. Knight & K. Laidlaw (Eds.) *Handbook of emotional disorders in older adults* (pp. 183–209). Oxford University Press.
- Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health*, 13, 143–154.
- Radloff, L. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.
- Reisberg, B., Ferris, S. H., de Leon, M. J., Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139, 361–369.
- Rodriguez, G., De Leo, C., Girtler, N., Vitali, P., Grossi, E., Nobili, F., (2003). Psychological and social aspects in management of Alzheimer's patients: an inquiry among caregivers. *Neurological Sciences*, 24, 329–335.
- Rudd, M. G., Viney, L. L., & Preston, C. A (1999). The Grief Experienced by Spousal Caregivers of Dementia Patients: the Role of Place of Care of Patient and Gender of Caregiver. *The International Journal of Aging and Human Development*, 48, 217–240.
- Sachs, G. A., Shega, J. W., Cox-Hayley, D. (2004). Barriers to Excellent End-of-life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19, 1057–1063.
- Scottish Government (2010). Scotland's National Dementia Strategy. Edinburgh.
- Scottish Government (2013). Scotland's National Dementia Strategy: 2013-16. Edinburgh.
- Scottish Government (2011a). Standards of care for dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy. Edinburgh.
- Scottish Government (2011b). National guidance that evidences the use of psychological therapies. Edinburgh.

Schultz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: the caregiver health effects. *Journal of the American Medical Association*, 282, 2215–2219.

Schulz, R., Beach, S.R., Lind, B., Martire, L. M., Zdanuik, B., Hirsch, C., Jackson, S., Burton, L. (2001). Involvement in caregiving and adjustment to death of a spouse: findings from the Caregiver Health Effects Study. *Journal of the American Medical Association*, 285, 3123–3129.

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961–967.

Schulz R., Newsom, J., Mittelmarm, M., Burton, L., Hirsch, C., Jackson, S. (1997). Health effects of caregiving: the Caregiver Health Effects Study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19, 110–116.

Schultz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The Gerontologist*, 35,771–791.

Schulz, R., & Williamson, G. M. (1994). Health effects of caregiving: Prevalence of mental and physical illness in Alzheimer's caregivers. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.) *Stress effects on family caregivers of Alzheimer's patients: Research and interventions* (pp. 38–63). New York: Springer.

Searson, R., Hendry, A.M., Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging & Mental Health*, 12, 276–282.

Sharp, L. K., & Lipsky, M. S. (2002). Screening for depression across the lifespan: a review of measures for use in primary care settings. *American Family Physician*, 15, 1001–1008.

Shim, B., Barroso, J., Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies*, 49, 220–229.

- Snyder, B., & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. *Social Work Health Care*, 10, 1–14.
- Spanier, G. B., & Thompson, L. A. (1982). A confirmatory analysis of the dyadic adjustment scale. *Journal of Marriage and Families*, 38, 731–741.
- Taylor, D. H., Ezell, M., Kuchibhatla, M., Ostbye, T., & Clipp, E. C. (2008). Identifying trajectories of depressive symptoms for women caring for their husbands with dementia. *Journal of the American Geriatrics Society*, 56, 322–327.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455–471.
- Teri, L., Logsdon, R. G., & Uomoto J., & McCurry, S. M. (1997). Behavioral treatment of depression in dementia patients: a controlled clinical trial. *Journal of Gerontology Series B Psychological Sciences*, 52, 159–166.
- Thoits, P. A. (2010). Stress and health: major findings and policy implications. *Journal of Health and Social Behavior*, 51, S41–S53.
- Train, G., Nurock, S., Kitchen, G., Manela, M., & Livingston, G. (2005). A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long-term care settings. *International Psychogeriatrics*, 17, 237–251.
- Van der Kooy, K., Van Hout, H., Marwijk, H., Marten, H., Stehouwer, C., & Beekman, A. (2007). Depression and the risk for cardiovascular diseases: systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*, 22, 613–626.
- Vitaliano, P. P., Young, H. M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *The Gerontologist*, 31, 67–75.
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972.

- Waite, A., Bebbington, P., Skelton-Robinson, M., Orrell, M. (2004). Social factors and depression in carers of people with dementia. *International Journal of Geriatric Psychiatry*, 19, 582–587.
- Walsh, J.S., Welch, H. G., Larson, E.B. (1990). Survival of outpatients with Alzheimer-type dementia. *Annals of Internal Medicine*, 113, 429–434.
- Williamson, G. M., & Schulz, R. (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging*, 5, 502–509.
- Winblad, B., Wimo, A., Almkvist, O. (2000). Outcome measures in Alzheimer's disease: do they go far enough? *Dementia and Geriatric Cognitive Disorders*. 11, 3–10.
- Wisniewski S., Belle, S. H., Coon, D., Marcus, S., Ory, M., Burgio, L., & Schultz, R. (2003) The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project design and baseline characteristics. *Psychology and Aging*, 18, 375–384.
- Wolfson, C., Wolfson, D.B., Asgharian, M., Emile, C., Ostbye, R., Rockwood, K., Hogan, D. B. (2001). A re-evaluation of the duration of survival after the onset of dementia. *The New England Journal of Medicine*, 344,1111–1116.
- Wright, L. K. (1994a). Alzheimer's Disease spousal caregivers: longitudinal changes in health, depression, and coping. *Journal of Gerontological Nursing*, 20, 33–48.
- Wright, L. K. (1994b). Alzheimer's disease afflicted spouses who remain at home: Can human dialectics explain the findings? *Social Science & Medicine*, 38, 1037–1046.
- Wright, F. (1998). *Continuing to care: the effect on spouses and children of an older person's admission to a care home*. Joseph Rowntree Foundation.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40, 147–164.
- Yesavage, J. A., Brink,T. L., Rose, T. L., Lum, O., & Huang, V. S. (1983). Development

and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37–39.

Zarit, S. H., & Gaugler, J. E. (2006). Care by families for late stage dementia. In A. Burns, & B. Winblad (Eds.) *Severe Dementia*. New York, NY: John Wiley & Sons Ltd.

Zarit, S.H., Reever, K., & Bach-Peterson, J. (1980). Relatives of impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 373–377.

Zarit, S. H., Todd, P. A., Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26, 260–266.

Zarit, S. H., & Whitlatch, C.J. (1992). Institutional placement: Phases of transition. *The Gerontologist*, 32,665–672.

Zung, W. W. K. (1965). A self-rating depression scale. *Archives of General Psychiatry*, 12, 63–70.

Chapter 2 The Research Context

2.1 INTRODUCTION

2.1.1 Dementia

Even with the best support, a person with dementia will experience profound effects in their life as a result of their disease. The decline in mental capacity and ability to function independently, together with the effect dementia may have on mood and behaviour, is highly distressing to the person with dementia themselves, and creates difficulties for carers as they seek to respond appropriately. (p.xvii, Nuffield Council on Bioethics, 2009).

2.1.2 Family carers

Caring for a loved one with dementia is a dynamic process that may last several years during which time the carer may experience loss of control associated with unpredictable deterioration (Ory *et al.*, 2000), cognitive loss and emotional and behavioural change (Pearlin, 1994) in the care recipient. Perhaps not surprisingly, knowledge about the experience of care-giving has been formed mainly from ‘burden’ (Ankri *et al.*, 2005; Herbert *et al.*, 2000; Zarit *et al.*, 1980), stress (Pearlin *et al.*, 1990) and coping (Pruchno & Resch, 1989) research that highlights the negative impact of care-giving on carer well-being (Hayley & Pardo, 1989).

2.1.3 Spousal carers

Research highlights that the experience of spousal dementia carers may differ from that of adult child carers, with greater depression and stress and lower social activities (Connell *et al.*, 2001; George & Gwyther, 1986; Pinquart & Sorensen, 2011). Spousal dementia carers in particular experience high levels of distress (Burton & Sistler, 1996; Coppel *et al.*, 1985) which may continue over time and beyond the death of the spouse (Tweedy & Guarnaccia, 2007). However, spousal carers receive limited research attention in their own right with few studies examining their experience as dementia progresses (Robinson *et al.*, 2005).

2.2 CARE TRANSITION

2.2.1 Placement in care

Spouses are less likely to place in care than adult children (Zarit & Whitlach, 1992) and report greater distress associated with care home placement (Eloniemi-Sulkava *et al.*, 2002; Gaugler *et al.*, 2010; Pinquart & Sorensen, 2011), and more frequent visits at care homes following placement (Wright, 1998) than other familial carers. While care home placement may be associated with opportunity for greater social activity for the carer (Matsuda *et al.*, 1997), it may also generate new distress if carers, as they transition to their new role as care manager, perceive that their spouse experiences poor care quality (Zarit & Whitlach, 1982; Gaugler *et al.*, 2000; Gaugler *et al.*, 2011).

The decision to place one's spouse in care is an emotive one which may be characterised by loneliness and sorrow (Eloniemi-Sulkava *et al.*, 2002), and negative attitudes such as abandonment and letting down one's spouse (Wright, 1998). Dementia carers are often required to make transition decisions without adequate support (Nolan & Dellasega, 2000). Spouses in particular may experience ambivalent emotional responses regarding the move to care home alongside difficulties in initiating and sustaining relationships with staff in care homes (Lundh *et al.*, 2000). The decision to place in care has been found to be predicted by carer well-being, including depression and stress (Bond *et al.*, 2003; Morycz, 1985; Riordan & Bennet, 1998; Townsend, 1990) although stress amongst spousal dementia carers may continue or increase following care home placement (Pagel *et al.*, 1985).

2.3 THE EVIDENCE BASE

2.3.1 The imbalance in carer research

There have been calls for research on the positive experience of spouses or partners of those with dementia with a view to supporting togetherness in couples living with dementia

(McGovern, 2011). Although the focus of carer research has predominantly been upon carer burden and stress, positive features in dementia care-giving have been noted more generally within care giver research (Kinny & Stephens, 1989; Motenko, 1989, Pinquart & Sorenson, 2004). However, positive experiences of care giving are less likely to come to the attention of mental health services and positive aspects of the care process, especially amongst spousal carers, remain understudied. There is a risk that we may miss valuable learning about resilience and sustainability in spousal care if this imbalance is not addressed.

2.3.2 Post traumatic growth

Post-traumatic growth is defined as the experience of positive change that occurs as a result of the struggle with highly challenging life crises (Tedeschi & Calhoun, 1996). The conceptual model of post traumatic growth posits that a traumatic event which disrupts underlying assumptions about goals, beliefs and meaning leads to emotional distress which in turn sets off a process of thinking, problem solving and sense making which may bring about psychological change (Tedeschi & Calhoun, 1996; 2004; Joseph & Linley, 2006).

The concept of positive growth has been used to study the dynamic experience of psychological change following crises including bereavement (Currier *et al.*, 2013; Edmonds & Hooker, 1992; Nerken, 1993) and chronic health conditions such as cancer (Cordova *et al.*, 2001; Widows *et al.*, 2005; Zwalen *et al.*, 2010). Positive growth has been examined in familial carers of those with multiple sclerosis (Pakenham, 2005) and cancer (Kim *et al.*, 2008) but has not yet been examined in spousal dementia carers.

Studying positive growth is important because of associations with improved well-being and adjustment for carers more generally which may be associated with reduction in the likelihood of care home placement (Gilley *et al.*, 2005). The study of positive growth

represents a move in the literature towards redressing the balance between positive and negative aspects of care.

2.3.3 Emotion regulation

The experience of emotions and the ability to process emotional distress when dealing with crises are considered to be fundamental in facilitating personal growth (Tedeschi & Calhoun, 2004, Aldwin & Levenson, 2004) and in shaping adaptive functioning (Phillips & Power, 2007). Gross & Thomson (2007) outline the fundamental role of emotions, in aiding or harming our interpersonal interactions, behaviours and decision making and highlight the importance of being able to regulate emotion successfully.

The common theoretical conceptualisation underpinning emotion regulation research is that of a process of conscious or automatic emotion modulation in response to environmental demands which involves changes in the dynamic experience of emotions that may sustain, intensify or dampen positive or negative emotion (Bargh & Williams, 2007; Gross & Munoz, 1995).

Emotions arise when something is important to us and the way in which we appraise an emotional situation shapes our response to it (Lazarus, 1991). Different regulation strategies have different consequences for perceptual, physiological and behavioural components of emotion (Campbell-Sills & Barlow, 2007) and appropriate emotion regulation strategies are important for health and well-being (Davidson *et al.*, 2000). Overuse of strategies such as suppression has been associated with anxiety (Campbell-Sills & Barlow, 2007) while cognitive reappraisal has been linked to successfully managing negative emotion (Gross, 1998).

It is not yet known how spousal dementia carers regulate their emotions, despite research that evidences the complex array of emotions experienced in caring for a partner with dementia (Malfullul & Morriss, 2000; Marwit & Meuser, 2002) and the adaptive function of emotion regulation strategies in managing emotions (Ochsner & Gross, 2004). Longitudinal research has demonstrated increased emotional stability and improved emotional regulation as people age (Carstensen *et al.*, 2011) although it is not known whether such improvements are maintained in times of adversity. Studying emotion regulation in spousal dementia carers at different stages in their care journey and examining the association between emotion regulation and positive growth may shape understanding of the relative adaptive functioning of strategies that are used.

2.4 SUMMARY

The crucial role of familial dementia carers is emphasised across the care giving evidence base and the experience may present particular challenges for spouses who care for their partner with dementia. There is potential to learn valuable lessons from positive experiences of care-giving and of the emotional experience of spousal dementia carers, yet these areas are under researched. It is not yet known whether spousal dementia carers experience positive growth or if there are particular emotional experiences and care transitions which may impact upon psychological change. It is hoped that the work undertaken in this thesis contributes to our understanding of the experience of emotion and positive growth in the care process and redresses the imbalance in predominantly negative stress and burden literature.

2.5 THESIS FOCUS

2.5.1 Aims

Aim 1: This thesis began by examining what happens to spousal dementia carers over time using a systematic review to summarise and critically appraise evidence from published

longitudinal studies that assess the impact of care transition on spousal dementia carers over time. This research is reported in chapter one, Systematic review: what happens to spousal dementia carer emotional well-being before and after care home placement?

Aim 2: This thesis examines spousal carers' experience and regulation of emotions and positive growth since taking on the role of carer and seeks to ascertain whether:

- experience and regulation of emotion in spousal dementia carers is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of spouse with dementia).
- adaptive emotion regulation strategies are associated with the experience of positive emotion.
- spousal dementia carers experience positive growth and if this is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of spouse with dementia).
- positive growth is moderated by the experience and regulation of emotions.

This research is reported in Journal article 2: Emotion regulation and positive growth in spousal dementia carers.

2.5.2 Hypotheses

Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies employed since taking on the role of spousal carer, for example, a significant positive relationship between happiness and adaptive emotion regulation strategies.

Hypothesis 2: Spousal dementia carers will experience positive growth.

Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

2.5.3 Clinical Implications

It is intended that the exploratory research in this thesis contributes to a broader understanding of the spousal carer experience and furthers understanding of some of the factors which shape the experience of caring for a partner with dementia. Research outputs will shape the care-giving evidence base and provide families, professionals and policy makers involved in the care process with information about the emotions experienced by carers, how they manage these emotions and whether they experience positive growth in the care journey. It is hoped that the work in this thesis will challenge assumptions about the homogeneity of dementia carers and their support needs and raise the profile of spousal carers as partners of people with dementia.

Chapter 3 Journal Article

Title: Emotion regulation and positive growth in spousal dementia carers

Authors:

Roisin Ash

NHS Grampian Psychology Department, Rosebank Cottage, Royal Cornhill
Hospital, Cornhill Road, Aberdeen AB25 2ZH

Tel: 01224 557474

Fax: 01224 557697

Email: roisin.ash@nhs.net

Professor Ken Laidlaw

University of East Anglia

3.1 ABSTRACT

Background: The emotional experience of spousal dementia carers has, predominantly, been understood in research and clinical practice through a narrow lens of negative emotional consequences. There is a need to contextualise the emotional experience of carers within a framework that enables understanding of positive aspects of the care experience.

Objective: This study examined the experience and regulation of emotions and positive growth in spouses who care for their partner with a diagnosis of dementia.

Methods: Empirical study comprising a cross-sectional design comparing positive growth and emotion regulation in three carer groups (caring for spouse at home, placed spouse in care home or experienced death of spouse). Carers were recruited through a postal survey which comprised the following self-report measures: Post Traumatic Growth Inventory; Basic Emotions Scale; and Regulation of Emotions Questionnaire.

Results: Spousal carers report more frequent feelings of fear and frustration compared to other basic emotions. Gender and care transition impact upon the experience and regulation of emotion and positive growth. Internalising emotion regulation strategies (e.g. rumination) are associated with greater fear and frustration, sadness and guilt while strategies comprising social support seeking are associated with feelings of happiness in carers. Spouses report positive growth since taking on the role of carer and this is predicted in part by social support seeking emotion regulation strategies but not by experience of emotions.

Conclusions: Spousal carers are not a homogenous group. Further research on the experience of spousal dementia carers is required including the development of tools and methods tailored to capture emotion regulation. The concept of positive growth following stressful events (for example, becoming a carer) may have potential for presenting an enriched understanding of the emotional consequences of the carer experience over time.

Keywords: spouse; carer; dementia; emotion; emotion regulation; transition; positive growth.

Key Practitioner Message:

- Those involved in supporting dementia carers may wish to examine the experience and regulation of emotions, including negative and positive emotions, and the role that these may have in shaping the care experience.
- Particular attention to the absence of social support seeking skills and use of internalising strategies in the presence of fear, frustration, guilt or sadness may highlight potential support needs.
- Spousal dementia carers living with their spouse most frequently use refocusing strategies to regulate their emotions. This may inform clinical intervention.
- Spousal dementia carers experience positive growth since taking on the role of carer and clinicians may wish to consider how positive aspects of the care experience can be used to support carers.
- Positive growth is associated with emotion regulation strategies that utilise social support and refocusing (perspective and planning) to manage emotions experienced since taking on the role of carer.

3.2 INTRODUCTION

3.2.1 *Spousal dementia carers*

Research demonstrates that spousal carers provide more care and experience greater psychological distress than other familial carers (Pinquart & Sorensen, 2011). Spousal dementia carers experience poorer health outcomes (Pinquart & Sorensen, 2007; Gonzalez et al., 2011) and greater anxiety and depression around the transition of care home placement (Schulz et al., 2004) than other familial carers. Dementia spousal carers are at higher risk of depression than non-carer spouses (Adams, 2008; Joling et al., 2010) and are at risk of depression following the death of spouse with dementia (Tweedy & Guarnaccia, 2007).

Carers also report experiencing positive aspects of caring for their spouse with dementia including shared activities (Searson et al., 2008), finding meaning (McLennan et al., 2011), and increased tenderness (Eloniemi-Sulkava et al., 2002) and closeness (DeVugt et al., 2003). Carers play a key role in supporting their spouse with dementia to live at home (Oyebode, 2003; Pinquart & Sorensen, 2011), providing continuity and support in maintaining their spouses personhood (Perry & O'Connor, 2002) and acting as mediators with social and health care networks (Jansson et al., 2001). A greater number of older couples will be faced with managing dementia as our population ages (Braun et al., 2009) and spousal dementia carers are, therefore, an important population to study (Martin et al., 2009).

3.2.2 *Experience of emotions in dementia care*

Dementia care may be characterised by a physical presence yet emotional absence of the spouse with dementia (Blieszner & Shifflett, 1990). Caring for a spouse with dementia presents many emotional challenges relating to uncertainty and loss (Boss, 2011) that may be heightened at care home placement (Lundh et al., 2000) and bereavement (Tweedy &

Guarnaccia, 2007). Sanders et al. (2008) describe spousal carers' grief as resulting from relationship changes, managing care home placement and ultimately death of their spouse.

Spousal carers may experience loss of companionship (Quinn et al., 2009), sadness, worry and isolation (Meuser & Marwit, 2001; Ott et al., 2007) as dementia progresses. Dementia reduces the ability of the spouse with dementia to provide emotional and practical support (Baikie, 2002) which may have been present in the past. The spouse with dementia may experience emotional disinhibition, lability, and dulling (Bromley, 1990) and the spousal carer, therefore, faces challenges in managing their own emotional reaction to changes in their spouse's emotional expression.

Depression has been found to correlate significantly with perceived lack of control over the carer's own emotional response as well as over their spouse's behaviour (Morris et al., 1989). Research has found that dementia carers who placed their spouse in care express greater guilt and grief than carers of spouses with physical illness (Tilse, 1998). Spaid & Baruch (1994) argue that, without emotional support, carers may experience difficulties which are enacted in the care situation including burn out, isolation and resistance to professional support.

3.2.3 Adaptation of carers

Caring for one's spouse has been described as mentally demanding and stressful (Braun et al., 2009) yet some carers adapt to their situation (Perren et al., 2006). Emotions have been described as psycho-evolutionary social constructs that have an adaptive function in survival (Harre, 1986; Plutchik, 1980). Expressed through experience and actions, emotions shape perception, interpersonal interaction, decision making and behaviour (Gross & Thomson, 2007).

Research demonstrates that coping strategies have a role to play in maintaining well-being amongst carers (Cooper et al., 2008). Strategies used to manage spousal dementia carers' emotional distress are more likely to be successful than attempts to manage situations that are outwith individual control (Pearlin & Schooler, 1978; Pruchno & Resch, 1989). Problem focused coping and affect regulation strategies have been associated with greater life satisfaction in dementia carers (Hayley et al., 1987).

Emotion regulation has been described as a subcategory of coping which focuses specifically on emotional goals (Gross, 1999). Ochsner & Gross (2004) argue that our capacity to adapt to a range of circumstances arises in part from our ability to regulate our emotions. Emotion-regulation strategies are used to modulate positive and negative emotions, either consciously or unconsciously, in response to environmental demands (Bargh & Williams, 2007; Gross & Munoz, 1995). It is argued that successful emotion regulation maintains arousal at a level where optimal social functioning is possible (Schoore, 2003, as cited in Chambers et al., 2009). Whether emotion regulation strategies are adaptive or maladaptive depends upon the particular social context, the emotion goal and the flexible use of strategies to manage changing situational demands (Marroquin, 2011).

Charles (2010) argues that emotional well-being is related to how skilled people are in regulating their emotions. Research has found that emotion regulation is important in maintaining psychological well-being when managing distress (Mauss et al., 2007), depression (Aldao et al., 2010) and satisfaction with relationships (Lopes et al., 2005). Emotion regulation strategies such as reappraisal and self-disclosure are associated with healthy adjustment while strategies such as catastrophising, emotion suppression and rumination are associated with less healthy adjustment including symptoms of depression and lack of social support (Campbell-Sills & Barlow, 2007; Campbell-Sills et al., 2006).

Emotion regulation strategies such as reappraisal have been found to be helpful amongst students in managing anger and frustration (Szasz et al., 2011) while strategies such as suppression have been associated with lower closeness and less social support (Graham et al., 2008). Symptoms of depression amongst inpatients have been found to be associated with fewer emotion regulation skills (Fehlinger et al., 2013). Depression has been found to be associated with greater use of strategies such as rumination and self-blame and less use of positive reappraisal and positive refocusing than is the case in age and gender matched controls (Ehring et al., 2008).

Given the heightened risk of depression amongst spousal dementia carers (Adams, 2008; Pinquart & Sorensen, 2011) and the demonstrated benefit of social support upon carers' subjective well-being (Elvish et al., 2013), the associations between emotion regulation strategies and depression and social support are noteworthy. Spousal dementia carers are faced with many challenging situations and interpersonal difficulties which elicit emotions and necessitate emotion regulation of the carer's own emotions as well as of the emotions of their spouse with dementia.

3.2.4 Emotion regulation in older adults

According to socioemotional selectivity theory, goals relating to emotions and emotionally meaningful experiences take priority over knowledge acquisition goals in later life and older adults are, therefore, more motivated than younger adults to use emotion regulation strategies to maintain emotional well-being (Carstensen, 2006). Magai et al. (2006) argue that life experience enables better prediction of one's own emotions and those of others which leads to more skilful emotion regulation.

Research demonstrates that older adults are more motivated and better able to regulate emotional responses than younger adults (Orgeta, 2009; Scheibe & Carstensen, 2010). Life experience is thought to improve skills of emotion regulation and confidence in their use in specific situations in older age (Blanchard-Fields, 2007; Scheibe & Blanchard-Fields, 2009). Charles (2010) argues that age-related decline in ability to control one's environment and decreased cognitive ability favour the use of emotion regulation strategies over trying to change the situation.

Age-related advantages in emotion regulation are believed to relate to greater use of antecedent strategies, which manage anticipated emotions and avoid emotionally challenging experiences, than response-focussed strategies which manage emotions after they occur (Charles & Carstensen, 2007). Spousal dementia carers may face unavoidable and emotionally challenging situations on a day-to-day basis which they may attempt to manage with the use of cognitive restructuring and problem solving (Scheibe & Carstensen, 2010).

However, Charles (2010) argues that exposure to chronic stressors such as spousal dementia care may impede age-related advantages in emotion regulation skills and cause a decrease in emotion regulation capacity. Longitudinal research has demonstrated increased emotional stability and improved emotional regulation with age, although it is not yet known if such improvements are maintained in times of adversity (Carstensen et al., 2011) such as living with the loss of a spouse with dementia over time.

Given that emotion regulation may be linked with broader life goals such as maximising positive emotional experience (Carstensen et al., 1999) and related to life experience about costs and benefits of using different emotion regulation strategies (Gross & John, 2002), it is of interest to consider if carers at different stages of their care journey experience different emotion profiles and whether they make different use of emotion regulation strategies.

3.2.5 *Positive Growth*

The concept of post traumatic growth (PTG), the experience of positive psychological change through adversity, provides a framework within which to examine positive psychological outcomes following situations of extreme stress (Schaeffer & Moos, 1992; Tedeschi & Calhoun, 1996; 2004). PTG refers to change or growth that is above and beyond the pre-crisis level of psychological functioning or adaptation (Tedeschi & Calhoun, 2004).

It is argued that growth or psychological change comprises increased personal strength, new priorities or new possibilities in life, positive spiritual change, or increased appreciation of life (Tedeschi et al., 1998). Furthermore, that psychological change in some or all of these areas may occur as a result of the crisis or through learning that occurs when attempting to cope with the crisis (Tedeschi & Calhoun, 1996).

Experiencing and processing emotional distress when managing crises are believed to be fundamental in facilitating positive growth (Tedeschi & Calhoun, 2004, Aldwin & Levensen, 2004) and in shaping adaptive functioning (Phillips & Power, 2007). However, Zoeller & Maercker (2006) argue that the role of emotions, most notably positive emotions, has been underestimated in PTG research when compared to the treatment of the role of cognitive factors.

Zoeller & Maercker (2006) describe traumatic events as linked to life threat and loss and argue that those who experience trauma develop an awareness of the fragility of life more generally. This description parallels the experience of many spousal dementia carers and it is possible that carers may experience growth as a result of their care journey. Positive growth has been examined in familial carers of those with chronic health conditions such as Multiple Sclerosis (Pakenham, 2005), HIV/AIDS (McCausland & Pakenham, 2003), and cancer (Kim et al., 2008).

3.2.6 The focus upon negative aspects of dementia care

The predominant focus in carer research on symptoms of depression, anxiety and burden means that the emotional experience of carers is not fully understood. While post traumatic growth has been examined in carers of those with chronic illness, it has not yet been examined in spousal dementia carers. Despite the emotional nature of caring for one's spouse with dementia and the importance of emotion regulation in adapting to stressful situations, a literature search uncovered no published work on emotion regulation amongst spousal dementia carers. There is a need to understand more fully the emotional experience of carers and the strategies used to regulate emotion and to examine the relationship between emotion regulation and positive growth. The current study focuses on deliberate strategies used to regulate emotions and perception of self-change as determined by self-report questionnaires.

3.2.7 Aims of the study

This study examines the relative frequency of emotions experienced by spousal dementia carers since taking on the role of carer and the strategies used to regulate these emotions, comparing spouses at different stages of care transition and explores the relationship between emotion regulation and positive growth.

The main aims of the current study were to examine the experience and regulation of emotions and positive growth amongst spousal dementia carers, and to ascertain whether:

1. experience and regulation of emotion in spousal dementia carers is moderated by carer gender or experience of care transition (care for spouse at home, placement of spouse in care home or death of their spouse with dementia).
2. adaptive emotion regulation strategies are associated with the experience of positive emotion.

3. spousal dementia carers experience positive growth and if this is moderated by carer gender or experience of care transitions (care for spouse at home, placement of spouse in care home or death of their spouse with dementia).
4. positive growth is moderated by the experience and regulation of emotions.

Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies employed since taking on the role of spousal carer, for example, a significant positive relationship between happiness and adaptive emotion regulation strategies.

Hypothesis 2: Spousal dementia carers will experience positive growth.

Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

3.3 METHODS

3.3.1 Design

The current empirical study employed a cross-sectional design comparing positive growth and emotion regulation in spousal carer groups at three different stages of care transition: (1) caring for spouse at home; (2) placed spouse in care home; and (3) experienced death of spouse. All carers completed a set of self-report measures that assessed emotions experienced (Basic Emotions Scale), emotion regulation (Regulation of Emotions Questionnaire), and positive growth (Post Traumatic Growth Inventory).

3.3.2 *Participants*

Participants were spousal dementia carers who were registered as members of the Scottish Dementia Clinical Research Network (SDCRN), a Scottish Government funded research network holding details of dementia carers who have consented to be contacted about dementia-related research across NHS in Scotland Health Board regions. Ethical approval (IRAS) was obtained for the study. All participants were contacted by mail. A total of 400 questionnaire packs were sent to the homes of carers resulting in 183 spousal carers participating in the research (representing a 46 per cent postal survey response rate).

3.3.3 *Measures of Emotion - The Basic Emotions Scale (BES)*

The term ‘basic emotions’ refers to the small set of cross-cultural universal emotions (Carolan & Power, 2011) and is associated with theories that emphasise the functional nature of emotions to provide information about and shape adaptive responses to situations that arise in life (Finucane et al., 2012). The Basic Emotions Scale (BES; Power, 2006) is a 20 item questionnaire that asks respondents to rate the frequency of emotions experienced in a given time frame (the trait version asks about emotions in general while the state version asks about emotions over the past week). Frequency of emotions are rated on a seven-point Likert Scale from 1 (not at all) to 7 (all of the time). Each scale item corresponds to one of five basic emotions and, therefore, total scores are available for each emotion. Five emotions were confirmed using a student population with good internal consistency (happiness ($\alpha = .83$); anger ($\alpha = .81$); fear ($\alpha = .79$); sadness ($\alpha = .84$); and disgust ($\alpha = .84$)).

The BES has been used in clinical populations including those with psychosis (Livingstone et. al., 2009), depression and anxiety (Power & Tarsia, 2007), bipolar disorder (Carolan & Power, 2011) and eating disorders (Fox & Froom, 2009) and has been used to explore the emotional experience of healthy and clinical groups, for example PTSD and chronic pain

(Finucane et. al., 2012). In the present research, respondents were asked to report on the frequency of emotions experienced generally (trait version) since taking on the role of carer for spouse or partner.

3.3.4 Measures - The Regulation of Emotion Questionnaire (REQ)

Self-report emotion regulation measures differ in focus and coverage of strategies examined. The Difficulties with Emotion Regulation Scale (Grazt & Roemer, 2004), for example, focuses mainly on dysfunctional strategies (for example, non-acceptance of emotional responses such as ‘when I’m upset, I believe that there is nothing I can do to make myself feel better’) whereas the Emotion Regulation Questionnaire (ERQ, Gross & John, 2003) covers positive cognitive reappraisal (modifying thoughts about an anticipated emotional situation to affect the emotional impact) and suppression (inhibiting emotion expression of current emotions).

The Regulation of Emotion Questionnaire (REQ, Phillips & Power, 2007) examines the relative use of both functional (planning, perspective) and dysfunctional emotion regulation strategies (repression and rumination) in response to emotions experienced. The REQ examines use of internal and external strategies (for example, I keep the feeling locked up inside and I talk to someone about how I feel, respectively).

The frequency of use of each emotion regulation strategy is scored on a 5-point Likert Scale from 1 (never) up to 5 (always). Validated for use with adolescents, each REQ item corresponds to one of four emotion regulation strategies with reasonable internal consistency (internal functional ($\alpha = .76$), internal dysfunctional ($\alpha = .72$), external functional ($\alpha = .66$) and external dysfunctional ($\alpha = .76$)). The REQ has been used to examine the use of emotion

regulation strategies in females with anorexia nervosa (Fox et al., 2012) and in adults who have experienced psychosis (Livingstone et al., 2009).

We deemed the relatively broader coverage of internal and external functional and dysfunctional strategies in the REQ to be useful for examining emotion regulation in spousal dementia carers, for the first time. The REQ was, therefore, used in the present study to examine the general frequency of use of emotion regulation strategies.

3.3.5 Positive Growth Measures - The Post Traumatic Growth Inventory (PTGI)

The Post Traumatic Growth Inventory (PTGI) is a 21-item self-report questionnaire that measures positive growth following adversity with good internal consistency ($\alpha = .90$, subscales ranging from $.67 - .85$) and test-retest stability reported at two months ($r = .71$) (Tedeschi & Calhoun, 1996).

PTGI items have been mapped onto five growth sub-scales (relating to others ($\alpha = .85$), new possibilities ($\alpha = .84$), personal strength ($\alpha = .72$), spirituality ($\alpha = .85$), appreciation of life ($\alpha = .67$) (Tedeschi & Calhoun, 1996). Linley et al. (2007) and Taku et al. (2008) have replicated the five factor structure although from one to four factors have also been reported using the PTGI (Anderson & Lopez-Baez, 2008; Ho et al., 2004; Linley et al. 2007; Sheikh & Marotta, 2005).

To date, opinions differ as to the most appropriate factor structure, although Ho et al. (2004) argue that the factor structure of the PTGI requires appropriate modification depending on the population being examined.

PTGI respondents rate questionnaire items (statements of positive growth) on a six-point Likert Scale from 0 (I did not experience this change) up to 5 (I experienced this change to a very great degree). Responses are summed to represent a total score (0 - 105) for degree of positive growth experienced. In the present study, the questionnaire was reworded to examine the extent of change “as a result of caring for your spouse/partner” rather than from “as a result of your crises”.

Post Traumatic Growth (PTG) as measured by the PTGI has been observed in adolescent, student, community or mixed college and community populations (Vishnevski et al., 2010). PTG has also been found in carers of spouses with cardiovascular illness (Senol-Durak et al., 2010), bereaved spouses (Boyras & Efstathiou, 2011), survivors of cancer (Morrill et al., 2008) and stroke (Ganstad et al., 2009) and was, therefore, used in the present study to examine post traumatic growth in spousal dementia carers.

3.3.6 Data Analysis

This study sought to examine emotion regulation and growth within and between three groups of spousal carers rather than to fit the data to previous models or compare with different clinical or adolescent populations. It is acknowledged that the questionnaires were being used for the first time in this population and, therefore, it was not known whether subscales found in previous research would apply to the participants in this study. Principal Components Analysis (PCA) was, therefore, conducted on responses to each scale (Costello & Osborne, 2005; Fabrigar et al., 1999; Phillips & Power, 2007) to assess how the data from each questionnaire reduced to a smaller set of composite variables whilst retaining information from the original variables (Fabrigar et al., 1999). Data reduction findings are reported in Section 1.

Section 2 addresses research aims 1 and 3 by examining the effects of care transition and gender on BES, REQ and PTGI scores using ANOVAs and independent t-tests. Section 3 addresses research aims 2 and 4 by examining the relationship between growth and experience and regulation of emotion with correlation and multiple regression analyses. Section 4 explores the relative frequency of emotions experienced, regulation strategies used to manage those emotions, and positive growth experienced within different care transition groups using paired carer transition group t-tests.

3.4 RESULTS

3.4.1 *Descriptive Statistics*

3.4.1.1 *Care transition*

Of the 183 carers, 131 (71 per cent) reported that they currently lived with their spouse at home, 29 (16 per cent) had placed their spouse in a care home and 23 (13 per cent) had experienced the death of their spouse with dementia. These three groups of spousal carers (living with spouse, placed spouse in care and experienced death of their spouse) did not differ significantly by ratio of males to females (Pearson's $\chi^2(2) = 0.34, p = 0.843$), age group ratio (Pearson's $\chi^2(8) = 6.51, p = 0.590$), and time together as a couple prior to taking on the role of carer caring ($F^{2,167} = 1.15, p = 0.238$). A one-way ANOVA revealed a significant effect of length of time caring on care transition ($F^{2,172} = 4.47, p = 0.013$) although post-hoc tests with Games-Howell procedure, appropriate for unequal sample sizes (Field, 2013), did not reach statistical significance (live with vs care home: $p = 0.086$, live with vs spouse deceased: $p = 0.221$, care home vs spouse deceased, $p = 0.960$). Descriptive statistics are displayed in Table 1.

3.4.1.2 Gender and age of spousal carers

The gender split was 46 per cent males and 54 per cent females with a significant association between gender and age (Pearson's $\chi^2(4) = 21.93$, $p = 0.000$). There were a disproportionately high percentage of females in the 66 - 80 years age group and disproportionately high percentage of males in the age 81 - 95 years group relative to expected levels if age was assumed as being equal in each gender. There were no significant differences between males and females in care transition ($p = 0.843$), time together before taking on the role of carer ($p = 0.870$) and in length of time in care role ($p = 0.321$).

3.4.1.3 Length of time caring for spouse with dementia

The average time together as a couple before taking on the role of carer was 44 years (SD = 11 years, range 8 - 68 years). The average length of time caring was 4.4 years (SD = 2.7 years, range 0.5 - 18 years). The majority of spouses in the sample reported caring for between two and five years (67 per cent).

Table 1. Descriptive statistics for participants by care transition

	Living at home with spouse n (%)	Placed spouse in care n (%)	Spouse is deceased n (%)	Total n (%)
Age group				
< 50 years	1 (1%)	0	0	1 (1%)
51 – 65 years	13 (10%)	6 (23%)	2 (10%)	21 (12%)
66 – 80 years	83 (66%)	17 (65%)	12 (57%)	112 (65%)
81 – 95 years	28 (22%)	3 (12%)	7 (33%)	38 (22%)
95+ years	1 (1%)	0	0	1 (1%)
Gender				
Male	61 (47%)	12 (41%)	10 (43%)	83 (46%)
Female	69 (53%)	17 (59%)	13 (57%)	99 (54%)
Mean length of relationship prior to care role	44.53 (10.64)	40.48 (13.05)	43.00 (13.32)	43.71 (11.39)
Range (in years)	8 - 63 years	12 - 68 years	19 - 60 years	8 - 68 years
Mean time caring (years)	4.00 (SD=2.47)	5.45 (SD=3.29)	5.20 (SD=2.98)	4.37 (SD=2.72)
Range (in years)	0.50 - 15 years	1.0 - 18 years	2 - 12 years	0.5 - 18 years
Total	131 (72%)	29 (15.8%)	23 (12.6%)	183 (100%)

3.4.2 Using the BES, REQ and PTGI with Spousal Dementia Carers

Principal Components Analyses were conducted on data from each of the three questionnaires (BES, REQ and PTGI) using SPSS (Version 19.0). Although the sample size

of 183 was below Comrey and Lee's (1992) criterion for a *fair* sample size for exploratory factor analysis ($n = 200$), the sample met *adequate* exploratory factor analysis sample size criterion ($n = 100$ to 200 with the majority of communalities above 0.5 , MacCallum et al., 1999).

Sampling adequacy indicated a pattern of correlations within each scale suited to factor analysis (Kaiser-Meyer-Olkin Measure of Sampling Adequacy of $.87$ (BES); $.71$ (REQ); $.90$ (PTGI)). Variables within each scale were correlated with each other and therefore data were appropriate for factor analysis (Bartlett's test of sphericity, $p < 0.0001$). Multicollinearity, examined using Variation Inflation Factor (VIF) and tolerance statistics, was within acceptable limits ($VIF < 4$, tolerance $> .20$, Field, 2013).

Our expectation was that a number of sub-scales would be interrelated within each questionnaire and this, in combination with the finding that the majority of factor correlations were greater than $.32$, warranted use of oblique rather than orthogonal rotation (Tabachnick & Fidell, 2007).

3.4.3 Section 1: Data Reduction and Scale Trimming

PCA enabled comparisons with factor structures reported in the literature (BES: Power, 2006; Power & Tarsia, 2007; REQ: Phillips & Power, 2007; and PTGI: Tedeschi & Calhoun, 1996; Anderson & Baez, 2008). Results showed both similarity and overlap with factors described in the literature as well as evidence for different sub-scale groupings and scale trimming. The results for each scale are discussed, in turn, below.

3.4.3.1 Experience of Emotions - The Basic Emotion Scale (BES)

PCA conducted on the BES yielded an initial five factor structure accounting for 68 per cent of common variance. Factor 5 was unstable, comprising two cross-loading items (anger and

loving) (Costello & Osborne, 1995). Following re-analysis, these items and a third low loading item (aggression loading < .45) were subsequently dropped from the analyses (Field, 2013; Stevens, 2009).

The resulting PCA conducted on 17 items yielded a four factor structure accounting for 70 per cent of common variance with the first factor accounting for most of the variance (42%). Table 2 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .49 to .90. The four factors were stable and interpretable. We acknowledge that the Kaiser method may inflate the number of factors although Cattell's (1966) scree plot test (Appendix 1) suggested a possible four factor solution.

Internal consistency on sub-scales was acceptable (Table 2). Disgust (renamed guilt in the present study), sadness and happiness (minus cross-loading item loving) were retained as factors in the current group of spousal dementia carers in line with factors reported by scale developers (Power 2006; Power & Tarsia, 2007) while frustration and irritation loaded with emotions previously reported as comprising fear to comprise the frustration and fear (tense) factor (Table 3).

Table 2. Mean, standard deviation (SD) and internal consistency of Basic Emotions Scale Factors

BES Factors	Eigenvalues	Variance Explained	Mean (SD)	Number	Cronbach's alpha
1.Tense	7.08	41.66%	3.90 (1.17)	170	$\alpha=0.89$
2.Sad	2.32	13.63%	2.87 (1.30)	165	$\alpha=0.86$
3.Guilty	1.47	8.65%	1.90 (1.14)	169	$\alpha=0.83$
4.Happy	1.03	6.09%	3.45 (1.34)	172	$\alpha=0.84$

Table 3. Data reduction of Basic Emotions Scale (BES) responses

BES Factor	Factor 1	Factor 2	Factor 3	Factor 4
BES Factor 1: Tension				
Frustration	0.91	-0.13	-0.05	-0.09
Tense	0.86	0.09	-0.08	0.02
Irritation	0.85	-0.27	0.15	-0.02
Worried	0.54	-0.27	0.15	-0.02
Anxiety	0.52	0.34	0.00	0.02
Nervousness	0.49	0.22	0.14	0.08
BES Factor 2: Sadness				
Misery	0.01	0.95	-0.11	0.00
Gloominess	-0.02	0.87	0.01	0.00
Mournful	-0.18	0.85	0.11	-0.02
Despair	0.34	0.55	-0.04	-0.09
BES Factor 3: Guilt				
Blameworthy	-0.06	-0.01	0.89	0.06
Humiliated	0.08	-0.11	0.86	-0.01
Shame	-0.02	0.08	0.75	-0.07
Guilt	0.14	0.16	0.63	0.00
BES Factor 4: Happiness				
Joy	-0.21	0.13	0.13	0.91
Happiness	0.06	0.02	-0.15	0.90
Cheerful	0.15	-0.22	0.02	0.83
BES: Excluded low loading (< .45) item and unstable factor				
Aggression	0.06	0.38	0.28	-0.04
Loving	0.11	0.18	-0.15	0.39
Anger	0.11	0.46	-0.07	0.14

3.4.3.2 Regulation of Emotions Questionnaire (REQ)

PCA conducted on the REQ with a fixed four factor structure to assess for internal and external dysfunctional and functional strategies (Phillips & Power, 2007; Livingstone et al., 2009) accounted for 47 per cent of common variance. Four items with low factor loadings were dropped from subsequent analysis (Field, 2013; Phillips & Power, 2007). The resulting PCA conducted on 17 items accounted for 54 per cent of common variance. Table 4 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .48 to .82. Cattell's scree plot test (Appendix 2)

suggested a possible four factor solution. Internal consistency was low on two sub-scales (Factors 3: externalise/hurt others and 4: refocus, Table 4).

Table 4. Mean, standard deviation (SD) and internal consistency of REQ Factors

REQ Factors	Eigenvalues	Variance explained	Mean (SD)	Number	Cronbach's alpha
1.Seek social support	3.33	19.59%	2.41 (0.69)	171	$\alpha=0.79$
2.Internalise/ruminate	2.81	16.54%	2.31 (0.60)	170	$\alpha=0.65$
3.Externalise/hurt others	1.54	9.08%	1.19 (0.29)	176	$\alpha=0.57$
4.Refocus	1.50	8.83%	2.94 (0.60)	177	$\alpha=0.54$

The resulting loadings of four factors obtained in this group of spousal dementia carers (Table 5) show overlap with factors reported in the literature (Phillips & Power, 2007). The external functional and dysfunctional factors retained the same items with the exception of two low loading items which were removed (exercise 'I do something energetic (e.g. play sport, go for a walk' and lashing out at objects 'I take my feelings out on objects around me, e.g. deliberately causing damage to my house or outdoor things').

Table 5. Data reduction of Regulation of Emotions Questionnaire (REQ) responses

REQ Factor (REQ strategy description, Phillips & Power, 2007)	Factor1	Factor 2	Factor 3	Factor 4
Factor 1: Social support seeking (external functional)				
1. I talk to someone about how I feel (expression of feelings)	0.81	-0.01	0.11	-0.03
20. I telephone friends or family (new item 1)	0.77	-0.02	-0.03	-0.01
3. I seek physical contact from friends or family (e.g. hug, hold hands)	0.73	0.10	-0.18	-0.14
21. I go out and do something nice (new item 2)	0.65	-0.20	0.05	0.12
8. I ask others for advice (advice seeking)	0.64	0.15	0.02	0.13
Factor 2: Internalising				
4.I review (rethink) my thoughts or beliefs (re-appraisal)	0.19	0.71	-0.04	0.10
15. I keep the feeling locked up inside (repression)	-0.38	0.69	-0.07	0.13
7. I dwell on my thoughts and feelings (rumination)	0.16	0.65	0.00	-0.38
9. I review (rethink) my goals or plans (modification of goals)	0.19	0.49	0.11	0.24
14. I think about people better off and make myself feel worse (negative social comparison)	-0.11	0.48	0.18	-0.10
Factor 3: Externalising (external dysfunctional)				
10. I take my feelings out on others physically (physical assault)	0.06	-0.09	0.80	0.00
17. I bully other people (bullying)	-0.04	-0.07	0.74	0.13
13. I try to make others feel bad (making others feel bad)	-0.14	0.16	0.62	0.01
2. I take my feelings out on others verbally (verbal assault)	0.12	0.27	0.59	-0.13
Factor 4: Refocusing (internal functional)				
11. I put the situation into perspective (perspective)	-0.11	-0.05	0.13	0.82
16. I plan what I could do better next time (planning)	0.01	0.39	-0.15	0.66
12. I concentrate on a pleasant activity (concentration)	0.27	-0.14	-0.01	0.65

REQ: Excluded low-loading items (< .45)				
5. I harm or punish myself in some way	-0.21	0.44	0.27	0.16
6. I do something energetic (e.g. play sport, go for a walk)	0.42	-0.02	-0.05	0.05
18. I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things)	0.03	0.05	0.39	-0.01
19. Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream)	0.03	0.35	0.19	-0.03

The internal functional factor retained three items (perspective, planning, concentration) while two items from this scale (re-appraisal and goal modification) loaded with items from the internal dysfunctional scale (repression, rumination, negative social comparison). Two low loading items were removed from the internal dysfunction scale (de-realisation: Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream) and self-harm: I harm or punish myself in some way).

As outlined in the introduction, the adaptive or maladaptive nature of emotion regulation strategies is context specific. No assumptions were made about the dysfunction of emotion regulation strategies used by spousal carers, rather the four retained factors were renamed as social support seeking (external functional), internalising (mixed internal functional with dysfunctional), externalising (external dysfunctional) and refocusing (internal functional). These sub-categories were used to examine response patterns in dementia carers in this study.

3.4.3.3 *Post Traumatic Growth Inventory (PTGI)*

PCA conducted on the PTGI yielded an initial five-factor structure accounting for 70 per cent of common variance. Four low loading items (< .45) were subsequently dropped from the analyses (Field, 2013; Stevens 2006). The resulting PCA conducted on 17 items yielded a five-factor structure accounting for 73 per cent of common variance, with the first factor accounting for most of the variance (44%). Table 6 displays the eigenvalues and variance explained by each factor before rotation. Promax rotation yielded item loadings ranging from .46 to .96 (Table 7). Internal consistency on sub-scales was acceptable. The five factor

solution using the Kaiser method replicates previous research (Tedeschi & Calhoun, 1996; Taku et al., 2008) although the scree plot suggests a one or five factor solution (Appendix 3).

Table 6. Mean, standard deviation (SD) and internal consistency of Post Traumatic Growth Inventory (PTGI) Factors

PTGI Factors	Variance explained	Eigenvalue	Mean (SD)	N	Cronbach's alpha
1.Appreciation & compassion	44.48%	7.56	2.43 (1.18)	175	$\alpha=0.85$
2.Relying upon others	8.24%	1.40	2.38 (1.26)	176	$\alpha=0.88$
3.New possibilities	7.50%	1.27	1.18 (1.08)	175	$\alpha=0.78$
4.Priorities and values	6.95%	1.18	2.79 (1.29)	177	$\alpha=0.71$
5. Spiritual change	6.10%	1.04	1.23 (1.54)	178	$\alpha=0.89$
Total PTGI score 17 items	73.26%		2.00 (0.97)	165	$\alpha=0.92$

Table 7. Data reduction of Post Traumatic Growth Inventory (PTGI) responses

PTGI subscales (and PTGI original subscales)	Factor				
	1	2	3	4	5
Factor 1: Strength and compassion (relating to others/personal strength/new possibilities)					
16. Put more effort into my relationships	0.83	0.05	0.17	-0.14	-0.08
15. More compassion for others	0.77	0.15	-0.16	0.14	0.03
17. More likely to try to change things	0.67	-0.01	0.03	0.10	0.05
19. Discovered I am stronger than I thought	0.61	0.01	0.02	0.14	0.14
12. Better able to accept the way things work out	0.46	0.04	0.18	0.29	-0.01
Factor 2: Relying upon others (relating to others)					
6. I see I can count on people	-0.11	0.91	0.02	-0.01	0.07
21. Better accept needing others	0.28	0.82	-0.09	-0.06	-0.08
8. Greater sense of closeness with others	-0.03	0.68	0.14	0.17	0.05
20. Learned about how wonderful people are	0.42	0.65	-0.02	-0.12	0.00
Factor 3: New possibilities (new possibilities)					
3. Developed new interests	-0.30	0.26	0.82	0.06	0.03
14. New opportunities are available	0.16	0.08	0.82	-0.22	-0.01
11. Able to do better things with my life	0.30	-0.19	0.80	-0.03	-0.05
7. Established a new path for life	0.03	-0.18	0.52	0.36	0.06
Factor 4: Priorities and values (appreciation of life)					
1.Changed priorities about what is important in life	0.19	-0.18	-0.09	0.86	0.02
2. Appreciation for value of my own life	-0.05	0.32	0.00	0.78	-0.12
Factor 5: Spiritual change (spiritual change)					
18. Have a stronger religious faith	0.15	-0.05	-0.04	-0.10	0.96
5. Better understanding of spiritual matters	-0.09	0.11	0.03	0.04	0.91
PTGI: Excluded low loading items (< .45)					
4. I have a greater feeling of self-reliance	0.03	0.21	0.18	0.42	0.07
9. I am more willing to express my emotions	0.06	0.35	0.25	0.40	-0.09
10. I know better that I can handle difficulties	0.42	0.22	-0.10	0.38	0.05
13. I can better appreciate each day	0.44	-0.10	0.08	0.25	0.26

The five obtained factors were interpretable for spousal carers and show similarities and differences with the original five factor solution reported by Tedeschi & Calhoun (1996). (Table 7). ‘Spiritual change’ and ‘Appreciation of life’ (minus low-loading item ‘I can better

appreciate each day’) were retained as factors in the current group of spousal dementia carers. ‘Relating to others’ retained four of seven items. Two items (‘I put more effort into my relationships’ and ‘I have more compassion for others’) loaded with two items in personal strength ‘I am better able to accept the way things work out’ and ‘I discovered I am stronger than I thought I was’. One low loading item was removed ‘I am more willing to express my emotions’. ‘New possibilities’ retained four of five items while ‘I am more likely to try to change things’ loaded onto a different factor. Two low loading personal strength items were removed ‘I know better that I can handle difficulties’ and ‘I have a greater feeling of self-reliance’.

3.4.4 Section 2: Care Transition, Gender, Emotion Regulation (BES and REQ) and Positive Growth (PTGI)

3.4.4.1 Research Aims 1 and 3

Two-way ANOVAs were used to examine interactions between gender and transition in emotion regulation (research aim 1) and positive growth (research aim 3). The primary focus was to ascertain whether there were heightened levels of sadness and guilt in carers who had placed their spouse in care or differences in the use of social support and rumination (internalising) emotion regulation strategies and positive growth between carer groups given the importance of these processes in facilitating growth (Tedeschi & Calhoun, 1996).

There were significant main effects of care transition on REQ internalising strategies, for example, rumination and repression ($F^{2,163} = 4.36, p = 0.014$), BES guilt ($F^{2,163} = 6.68, p = 0.002$), sadness ($F^{2,158} = 8.04, p = 0.000$), and total PTGI scores ($F^{2,159} = 5.30, p = 0.006$). There were no significant gender and transition interactions (internalising: $p = 0.829$, guilt: $p = 0.379$, sadness: $p = 0.723$, PTGI: $p = 0.072$) and no significant main effects of gender on

these measures (internalising: $p = 0.358$, guilt: $p = 0.872$, sadness: $p = 0.161$, PTGI: $p = 0.057$). There was a significant main effect of transition ($F^{2,164} = 5.96$, $p = 0.003$) and gender ($F^{1,164} = 16.96$, $p = 0.000$) for social support seeking and no significant gender and transition interaction ($p = 0.192$).

Post hoc comparisons were conducted with Bonferroni tests to control for Type 1 error rate (Field, 2013), and Cohen's d (Cohen, 1992) for effect size. Carers who had placed their spouse in care reported significantly higher BES sadness ($p = 0.000$, $d = .81$) and guilt ($p = 0.001$, $d = .80$), greater use of REQ social support seeking ($p = 0.016$, $d = .56$) and internalising strategies such as rumination and repression ($p = 0.021$, $d = .59$) and greater positive growth (PTGI, $p = 0.043$, $d = .53$) than those who live with their spouse. Means by care transition are shown in Table 8.

Table 8. Mean Basic Emotions (BES) scores, Emotion Regulation (REQ) scores and Post Traumatic Growth (PTGI) scores by care transition

	Currently living with spouse			Placed spouse in care			Experienced death of spouse			Total		
	Mean	(SD)	N	Mean	(SD)	N	Mean	(SD)	N	Mean	(SD)	N
BES Factor												
Tense	3.82	(1.11)	121	4.18	(1.33)	20	3.94	(1.27)	20	3.90	(1.17)	170
Happy	3.58	(1.32)	120	3.13	(1.34)	23	3.14	(1.37)	23	3.45	(1.34)	172
Sad**	2.65**	(1.26)	116	3.69**	(1.31)	22	3.07	(1.10)	22	2.87	(1.30)	165
Guilty*	1.74*	(0.96)	121	2.62*	(1.56)	20	1.89	(1.14)	20	1.90	(1.14)	169
REQ Factor												
REQ Refocusing	2.94	(0.59)	127	2.95	(0.59)	29	2.87	(0.65)	21	2.94	(0.60)	177
REQ Social support	2.30**	(0.65)	122	2.66**	(0.69)	28	2.70	(0.80)	21	2.41	(0.69)	171
REQ Internalising	2.23**	(0.60)	122	2.58**	(0.52)	27	2.43	(0.59)	21	2.31	(0.60)	170
REQ Externalising	1.21	(0.31)	125	1.18	(0.24)	28	1.11	(0.21)	23	1.19	(0.29)	176
PTGI factor												
Values	2.77	(1.26)	129	2.87	(1.04)	27	2.81	(1.79)	21	2.79	(1.29)	177
Strength	2.31	(1.18)	127	2.73	(1.01)	26	2.79	(1.30)	22	2.43	(1.18)	175
Relying	2.26	(1.27)	126	2.71	(1.09)	28	2.67	(1.37)	22	2.38	(1.26)	176
Spirituality	1.07*	(1.40)	129	2.04*	(1.86)	28	1.14	(1.61)	21	1.23	(1.54)	178
New possibilities	0.95**	(0.90)	128	1.73**	(1.18)	27	1.93**	(1.41)	20	1.18	(1.08)	175
PTGI Mean 17 item	1.87*	(0.93)	122	2.39*	(0.83)	23	2.36	(1.19)	20	2.00	(0.97)	165
PTGI Mean 21 item~	1.92*	(0.97)	119	2.42*	(0.79)	23	2.31	(1.15)	19	2.04	(0.99)	161
PTGI Total Score~	40.40*	(20.39)	119	50.87*	(16.69)	23	48.58	(24.33)	19	42.86	(20.72)	161

* $p < 0.05$, ** $p < 0.01$ ~PTGI 21-item scores are shown to enable meaningful comparison with previous research

3.4.4.2 Further Exploratory BES Emotions Analyses

Further exploratory analyses on BES emotions revealed significant main effects of gender on happiness ($F^{2,165} = 7.66, p = 0.006$) and fear with frustration ($F^{2,163} = 7.54, p = 0.007$). There was no main effect of care transition (happiness: $p = 0.075$, fear with frustration: $p = 0.399$) and no significant gender and transition interaction (happiness: $p = 0.796$, fear with frustration: $p = 0.935$). Posthoc gender comparisons, Bonferroni corrected for multiple comparisons, revealed that females report significantly greater fear with frustration ($p = 0.007, d = 0.61$), happiness ($p = 0.006, d = 0.44$) and social support seeking ($p = 0.000, d = 0.79$) than males. Means by gender are displayed in Table 9.

Table 9. Mean Basic Emotions (BES) and Emotion Regulation (REQ) scores by gender

	Female			Male		
	Mean	SD	Number	Mean	SD	Number
BES Factor						
Tense	4.22**	(1.03)	92	3.53**	(1.22)	77
Happy	3.72*	(1.24)	92	3.14*	(1.39)	79
Sad	3.10	(1.31)	88	2.61	(1.25)	76
Guilty	1.98	(1.18)	92	1.81	(1.09)	77
REQ Factor						
REQ Social support	2.64**	0.68	93	2.12**	(0.61)	77
REQ Internalise	2.38	0.58	93	2.23	(0.62)	76
REQ Externalise	1.21	0.31	95	1.17	(0.25)	80
REQ Refocus	3.04	0.61	96	2.83	(0.55)	80

* $p < 0.005$, ** $p < 0.001$

These results suggest that males and females were not affected differently by care transition in regards to their feelings of guilt and sadness and in their use of internalising strategies.

Placement in care was associated with increased guilt and sadness and use of internalising regulation strategies and with increased positive growth for males and females (Figure 1).

Females at all care transition stages reported greater use of social support seeking than males which paralleled total growth scores (Figure 2). It should be noted that numbers in the gender by transition groups were small and these results are only illustrative of trends in the data and should be interpreted cautiously.

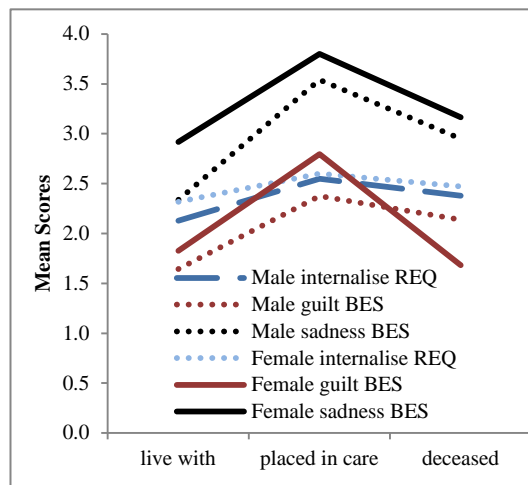


Figure 1 BES and REQ scores by gender and transition

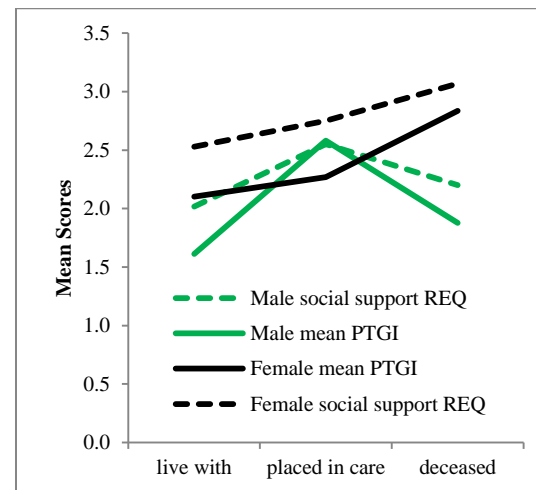


Figure 2 Social support and PTGI scores by gender and transition

3.4.4.3 Exploring Comparisons of Positive Growth with Published Findings

Although results from using the PTGI in the present sample of spousal carers provided evidence for scale trimming, total scores on the 21-item PTGI scale were reported to enable comparison with results reported in other populations in published literature. Total PTGI scores represent degree of reported change (ranging from no change (0), very small degree (21), small degree (42), moderate degree (63), great degree (84), and very great degree (105) of change).

Results in the present study with spousal dementia carers showed that a ‘small degree’ of positive growth was reported since taking on the role of spousal carer (mean total overall PTGI score 21-item = 42.86, SD = 20.72). The results were lower than reported by Tedeschi & Calhoun (1996) in their original study of female and male students (total PTGI scores of 75.18 (SD = 21.24) and 67.77 (SD = 22.07), respectively). Findings in the present study of spousal dementia carers are in line with results in an adult sample of husbands (mean = 46.00 SD = 22.83) whose wives had been diagnosed with cancer (Weiss, 2002).

3.4.5 Section 3. Exploring the Relationship between Positive Growth, Emotion and Emotion Regulation

3.4.5.1 Research Aims 2 and 4: Partial correlations

Partial correlations were undertaken to examine the relationship between emotion regulation and experienced emotion (research aim 2) and with positive growth (research aim 4). The interest was in examining whether adaptive emotion regulation strategies are associated with the experience of positive emotion and positive growth is moderated by the experience and regulation of emotions. Gender and care transition were controlled for because of statistically significant effects upon BES, REQ and PTGI scores (reported above in section 3.4.4). Total PTGI scores provide an indication of positive growth whereas scores from each sub-scale of the BES and REQ are interpretable. Total scores from the PTGI were, therefore, used with BES and REQ sub-scale scores in the correlation analyses. Correlations are shown in Table 10, below.

Table 10. Partial correlations between BES, REQ and PTGI scores

	REQ Social support	REQ Refocusing	REQ Internalising	REQ Externalising	PTGI Total
BES Tense	.12	-.03	.58**	.19	.20*
BES Sad	.02	-.23	.56**	.32**	.02
BES Guilty	.09	-.11	.50**	.28**	.19*
BES Happy	.27**	.26**	-.18	-.08	.19*
PTGI Total	.45**	.37**	.15	.01	

* $p < 0.05$, ** $p < 0.001$

The experience of positive emotion (happiness) correlate positively with emotion regulation strategies that involve seeking social support and constructive refocusing ($r = .27$ and $r = .26$, $p = 0.005$). The experience of negative emotions (sadness and guilt) correlate positively with REQ internalising ($r = .56$, $p = 0.001$: sadness and $r = .50$, $p = 0.001$: guilt) and REQ externalising strategies ($r = .32$, $p = 0.001$: sadness and $r = .28$, $p = 0.005$: guilt).

Positive growth and positive and negative BES emotions were positively and significantly correlated (fear with frustration ($r = .21, p = 0.013$), guilt ($r = .19, p = 0.024$), happiness ($r = .20, p = 0.020$). This suggests that experience of mixed and conflicting emotions relating to fear with frustration, guilt and happiness may play a role in the experience of positive growth. Positive growth and emotion regulation strategies seeking social support and refocusing correlated positively and significantly ($r = .45, p = 0.000$ and $r = .37, p = 0.000$, respectively). This suggests that use of social support seeking and refocusing efforts constructively may facilitate positive growth.

3.4.5.2 Relationship between positive growth, experience and regulation of emotion

A multiple hierarchical regression was carried out to examine the contributory effect of experience and regulation of emotion, taken together, upon positive growth (Research aim 4). The present correlation analyses and background literature which highlights the key role of social support in the experience of positive growth (Tedeschi & Calhoun, 1996) governed the order in which variables were entered into the regression analysis. Gender and transition were entered as control variables followed by step-wise addition of the REQ factor seeking social support, then constructive refocusing. BES factors, tension and guilt, were then entered, followed by the BES variable, happiness. Remaining REQ and BES factors were not included due to non-significant correlations with PTGI total scores as reported above.

Emotion regulation strategies that include seeking social support and constructively refocusing efforts explained a low level of the variation in positive growth scores (24 per cent). Including the experience of emotions relating to factors tense and guilty explained an additional 3 per cent of the variation in positive growth scores although including these variables and the variable happiness made no significant contribution to the model (all $p > 0.05$, as shown in Table 11 (p value)).

Table 11 Linear model of predictors of positive growth scores in dementia carers

Variable (N=139)	B (SE B)	β (p value)
Step1		
$R^2=0.12$, Adjusted $R^2=0.11$, $p<0.0001$		
Constant	1.52 (0.15)	$p<0.0001$
Gender	0.52 (0.16)	0.27 ($p=0.001$)
Transition	0.13 (0.05)	0.21 ($p=0.01$)
Step2		
$R^2=0.28$ Adjusted $R^2=0.26$, $\Delta R^2=0.16$, $p<0.0001$		
Constant	0.35 (0.26)	$p=0.17$
Gender	0.22 (0.15)	0.11 ($p=0.16$)
Transition	0.07 (0.05)	0.11 ($p=0.17$)
Seeking Social Support	0.60 (0.11)	0.44 ($p<0.0001$)
Step3		
$R^2=0.36$ Adjusted $R^2=0.34$, $\Delta R^2=0.08$, $p<0.0001$		
Constant	0.86 (0.38)	$p=0.03$
Gender	0.19 (0.15)	0.10 ($p=0.19$)
Transition	0.09 (0.05)	0.14 ($p=0.06$)
Seeking Social Support	0.48 (0.11)	0.35 ($p<0.0001$)
Refocusing efforts	0.50 (0.12)	0.30 ($p<0.0001$)
Step4		
$R^2=0.39$ Adjusted $R^2=0.36$, $\Delta R^2=0.03$, $p<0.05$		
Constant	-1.32 (0.42)	$p=0.002$
Gender	0.13 (0.15)	0.07 ($p=0.39$)
Transition	0.07 (0.05)	0.10 ($p=0.15$)
Seeking Social Support	0.44 (0.11)	0.32 ($p<0.0001$)
Refocusing efforts	0.53 (0.12)	0.32 ($p<0.0001$)
BES tension	0.09 (0.08)	0.11 ($p=0.23$)
BES guilt	0.10 (0.07)	0.12 ($p=0.17$)
Step5		
$R^2=0.40$ Adjusted $R^2=0.37$, $\Delta R^2=0.01$, $p=0.14$		
Constant	-1.53 (0.44)	$p<0.0001$
Gender	0.08 (0.15)	0.04 ($p=0.60$)
Transition	0.07 (0.05)	0.11 ($p=0.11$)
Seeking Social Support	0.40 (0.11)	0.29 ($p<0.0001$)
Refocusing efforts	0.49 (0.12)	0.30 ($p<0.0001$)
BES tension	0.12 (0.08)	0.14 ($p=0.12$)
BES guilt	0.10 (0.07)	0.12 ($p=0.17$)
BES happiness	0.09 (0.06)	0.12 ($p=0.14$)

3.4.6 Section 4: Exploring the Relative Frequency of Emotions Experienced and Emotion Regulation Strategies used by Spousal Dementia Carers Since Taking on the Role of Carer

3.4.6.1 Within Group Comparisons

Results from paired t-tests examining the relative frequency of emotions, emotion regulation and growth are shown in Table 12, below, with Bonferroni correction for multiple comparisons. Results show that there are similarities and differences in relative frequencies reported within different carer groups. Overall, externalising strategies (for example, bullying, making others feel bad) were used the least frequently and guilt reported least frequently by spousal carers.

3.4.6.2 Living with spouse

Carers who currently live with their spouse reported similar levels of positive (happiness) and negative emotion (fear with frustration) and experienced these emotions more frequently than sadness and guilt. Emotion regulation strategies comprising constructive refocusing (perspective, planning and concentration) were used more frequently than other strategies.

There was significantly greater positive growth in ‘priorities and values’ than in other PTGI domains.

3.4.6.3 Placed Spouse in Care

Carers who had placed their spouse in care reported significantly more sadness than guilt, significantly more fear with frustration (tension) than happiness and guilt, and similar frequency of use of social support seeking, refocusing and internalising strategies (for example, rumination, repression). Carers reported significantly greater growth in ‘strength and compassion’ and ‘relying upon others’ compared with ‘new possibilities’

3.4.6.4 Experienced the Death of Spouse

Carers whose spouse was deceased reported significantly greater fear with frustration than other emotions and similar frequency of use of social support seeking, refocusing and internalising strategies. Significantly greater growth was reported in ‘priorities and values’ and ‘strength and compassion’ than ‘new possibilities’.

Table 12. Within group t-tests for BES, REQ and PTGI scores

	Live with spouse N=125		Placed in care N=26		Spouse is deceased N=20	
BES Within Group Comparisons*	t value	probability	t value	probability	t value	probability
Tense versus Happy	1.26	0.210ns	3.30	0.003	3.02	0.007
Tense versus Sad	12.01	0.000	2.85	0.009ns	5.34	0.000
Tense versus Guilty	24.32	0.000	7.01	0.000	6.09	0.000
Happy versus Sad	4.73	0.000	1.70	0.102ns	0.06	0.950ns
Happy versus Guilty	11.15	0.000	1.34	0.192ns	3.31	0.004
Sad versus Guilty	9.04	0.000	4.96	0.000	4.08	0.001
REQ Within Group Comparisons*	*Bonferroni corrected p < 0.008 level of significance					
Refocus vs Social	10.69	0.000	1.50	0.480ns	0.93	0.363ns
Refocus vs Internalise	9.24	0.000	2.35	0.027ns	2.47	0.022ns
Refocus vs Externalise	26.55	0.000	13.66	0.000	12.11	0.000
Social vs Internalise	0.78	0.440ns	0.72	0.480ns	1.49	0.153ns
Social vs Externalise	16.64	0.000	10.05	0.000	8.67	0.000
Internalise vs Externalise	20.37	0.000	13.25	0.000	10.25	0.000
PTGI Within Group Comparisons*	*Bonferroni corrected p < 0.005 level of significance					
Priorities/Values vs Strength and compassion	4.23	0.000	0.06	0.949ns	0.17	0.869ns
Priorities/Values vs Relying on others	4.21	0.000	0.50	0.623ns	0.47	0.647ns
Priorities/Values vs New possibilities	16.98	0.000	3.98	0.001	3.18	0.005
Priorities/Values vs Spirituality	12.82	0.000	2.02	0.054ns	4.30	0.000
Strength/compassion vs Relying on others	0.37	0.713ns	0.48	0.635ns	1.23	0.233ns
Strength/compassion vs New possibilities	15.22	0.000	4.37	0.000	5.12	0.000
Strength/compassion vs Spirituality	10.73	0.000	2.97	0.006ns	4.75	0.000
Relying on others vs New possibilities	13.26	0.000	3.66	0.001	2.47	0.023
Relying on others vs Spirituality	9.77	0.000	2.10	0.045ns	4.33	0.000
New possibilities vs Spirituality	0.90	0.368ns	0.95	0.352ns	2.10	0.049ns

3.5 DISCUSSION

3.5.1 Summary of key findings

The findings from examining basic emotions, emotion regulation and positive growth experienced since taking on the role of caring for one's spouse with dementia suggests that carers experience a range of emotions that may be described as positive and negative, both simultaneously and separately, and that positive growth is experienced by spousal dementia carers. The results demonstrate that spousal carers are not a homogenous group and experience positive growth and use emotion regulation strategies differently to manage emotions experienced since taking on the role of carer. Key research findings are summarised and followed by discussion and consideration of study limitations, clinical implications and research recommendations.

3.5.2 Hypothesis 1: There will be a significant relationship between the experience of emotion and emotion regulation strategies used since taking on the role of carer.

Findings are summarised as follows:

- Carers who have placed their spouse in a care home report significantly more frequent feelings of fear and frustration compared to happiness while those living with their spouse report similar frequency of happiness and fear and frustration.
- Carers who live with their spouse report more frequent use of constructive refocusing (perspective, planning and concentration) than other emotion regulation strategies.
- Greater frequency of happiness is associated with greater use of constructive refocusing strategies.
- Greater frequency of sadness, guilt and fear and frustration is associated with greater use of internalising strategies.
- Carers who have placed their spouse report significantly greater frequency of guilt and sadness and greater use of internalising (for example, rumination, repression)

and social support seeking regulation strategies compared to carers who live with their spouse.

- Greater frequency of happiness is associated with greater use of social support seeking in carers.
- Females report significantly greater fear and frustration and happiness than males and significantly greater use of social support seeking emotion regulation strategies.
- All carers report infrequent use of externalising strategies (verbal assault, bullying others) to manage emotions and guilt is the least frequently reported emotion in all carers.

Fear and frustration were experienced frequently by spousal dementia carers in this study yet these are relatively under researched in this population. For example, systematic review of dementia carer anxiety demonstrated that research has focused upon psychological problems including psychological distress and symptoms of depression rather than examine the experience of worry and fear (Cooper et al., 2007). Qualitative research has found that fear in spousal dementia carers is associated with uncertainty of dementia progression and ability to cope with future unknown care needs, loss of control and loss of the cared for relative (Lindgren et al., 1999; O'Shaughnessy et al., 2010). Bramble et al. (2009) argue that fear about dementia progression may inhibit spousal dementia carers from seeking help.

Female carers experience higher levels of perceived threat and frustration than male carers in regard to physically aggressive behaviours associated with dementia (Bedard et al. 2005) and are more likely to report negative impact and lack of confidence in managing physical behaviours than male carers (Collins & Jones, 1997; Robinson et al. 2001). This may, in part, account for the greater frequency of fear and frustration reported by females in the present study. Females reported feeling happy more frequently than males with significantly

greater use of social support seeking. This concurs with previous studies which report significantly greater use of social support seeking coping (Tamres et al., 2002) and of emotion support seeking emotion regulation in females than males (Nolen-Hoeksema & Aldao, 2011). The findings of the present study suggest that social support seeking strategies in carers may help to manage difficult emotions such as fear and frustration and enhance positive emotions such as happiness.

Happiness is an emotion which is not widely associated with spousal dementia care in the research literature although, in this study, spousal carers who live with their spouse reported significantly greater positive affect (happiness) than sadness and guilt and greater use of constructive refocusing (for example 'I put the situation into perspective', 'I plan what I could do better next time') than other emotion regulation strategies. In contrast, carers who have placed their spouse in care or experienced the death of their spouse reported similar frequency of happiness, sadness and guilt and similar frequency of use of internalising, refocusing and social support strategies.

These findings may be understood by considering that involvement in activities that have purpose and personal meaning are likely to be supportive in maintaining psychological well-being (Laidlaw & Thompson, 2008) and that positive affect is increasingly associated with meaning in life as age increases (Hicks et al., 2012). Co-habiting may enable spousal carers to focus upon positive emotion goals and to derive meaning in life through the opportunities presented in the care role which may not be available when living apart from one's spouse either through placement or bereavement. The care role may require regular use of refocusing strategies such as planning and putting things into perspective to manage the emotions that arise to enable a selective focus on obtaining positive rather than negative goals (Carstensen et al., 2011).

Spouses whose role as carer has shifted either through care home placement or death experienced significantly greater fear and frustration than happiness and, in comparison to carers who live with their spouse, reported greater sadness, guilt and use of internalising strategies (rumination, repression). Emotion regulation strategies such as rumination have been associated with less healthy adjustment including symptoms of depression and lack of social support (Campbell-Sills & Barlow, 2007; Campbell-Sills et al., 2006; John & Gross, 2007). Self-blame and less use of positive refocusing have also been associated with depression (Ehring et al., 2008). Carers who experienced care home placement or death of their spouse used social support significantly more frequently than carers who live with their spouse which may be a more important and protective strategy in managing emotions that arise following care transition.

It was surprising that guilt was the emotion reported least frequently by all carers given that guilt has been associated with psychological distress commonly experienced by familial dementia carers (Croog et al., 2006; Gonyea et al., 2008; McConaghy & Caltabiano, 2005). Qualitative research has found that spousal dementia carers report guilt, most notably in relation to managing the tension in meeting their spouses needs and their own needs (O'Shaughnessy et al., 2010) and to uncertainty regarding whether spouses are consenting to sexual activity (Baikie, 2002).

The association between care home placement and greater frequency of guilt in the present study is, however, in line with qualitative research which demonstrates heightened guilt and sadness in response to placing one's spouse in care (Rudd, 1999; Finch, 1995; Lundh et al., 2000; Tilse, 1998; Wright, 1998) which may continue over a number of years after care home placement (Hennings et al., 2013; Ryan & Scullion, 2000). Anticipation of care home placement may also be associated with feelings of guilt and sadness and, combined with the

view of care home placement as a last resort, may be associated with the high frequency of care home placements that occur at times of crisis (Nolan & Dellasega, 2000).

There are a lack of empirical studies that examine the experience of guilt amongst dementia carers (Gonyea, 2008) which has been attributed to a lack of appropriate empirical measures for this population (Roach et al., in submission, 2013). The Caregiver Guilt Questionnaire has recently been validated for use in clinical and research settings in the UK (Roach et al., 2013, in submission) which may, in future, encourage the assessment of guilt at different stages of the care journey.

Fear and frustration were commonly experienced by all carers in the present study which may suggest that this is a particular area that intervention and support packages may wish to target in future. The finding that happiness is experienced by all carers and may be enhanced by social support or constructive refocusing strategies (where there are meaningful, purposive activities to undertake) is important in light of findings that suggest that positive emotions support recovery from the impact of negative emotions (Tugade & Fredrickson, 2004) and may inform carer interventions.

3.5.3 *Hypothesis 2: Spousal dementia carers will experience positive growth.*

Findings:

- Spousal dementia carers experience positive growth after taking on their care role.
- Carers who have placed their spouse in care report significantly greater positive growth than carers who live with their spouse, most notably in domains of ‘spirituality’ and ‘new possibilities’.
- Carers who have experienced the death of their spouse report significantly greater ‘new possibilities’ than carers who live with their spouse.

The present study found that positive growth, as measured by the PTGI, was evident among dementia caregivers, including those who are currently active in the care role, and was shaped, in part, by care transition and emotion regulation. Total positive growth scores in the present study were lower than the original study of students who had experienced a negative life event in the past five years including bereavement, accident and parental divorce (Tedeschi & Calhoun, 1996) and in line with scores reported in older adults whose spouses had been diagnosed with cancer (Weiss, 2002).

Tedeschi & Calhoun's (1996) sample comprised younger participants than the present study which may generate greater growth because of greater openness to learning and change in the context of trauma in younger participants (Tedeschi & Calhoun, 2004). Caring for one's spouse with dementia in later life is likely to be qualitatively different to adjusting to trauma experienced at university. Living daily with ambiguous loss, complicated grief, chronic sorrow and lack of closure (Boss, 2011) may differentiate the degree of growth experienced in spousal carers from other study populations. Intense demands of the carer role (Scarff & Zultner, 2012) may prohibit growth with limited opportunities, for example, to develop new interests or establish new paths. It was notable that carers who no longer lived with their spouse either through care home placement or death experienced greater growth in 'new possibilities'.

3.5.4 Hypothesis 3: There will be a significant positive relationship between adaptive emotion regulation strategies and positive growth.

Findings:

- Positive growth since taking on the role of carer is predicted in part by social support seeking and constructive refocusing emotion regulation strategies but not by the experience of emotions.

Tedeschi & Calhoun (1996) argue that schema change contributes to the experience of growth although schema change relies upon managing emotional distress to the extent that cognitive processing can take place. Growth in the present study was predicted partly by emotion regulation, a subcategory of coping (Gross, 1999) which facilitates adaptation to a range of circumstances (Ochsner & Gross, 2004) and not by experience of emotions. This suggests that it is what carers do to manage the emotion that facilitates growth. The present findings suggest that carers who are enabled to manage their emotions pro-actively are more likely to experience positive growth. These findings have implications for carer interventions which may usefully include support to develop emotional awareness and ways to regulate and manage emotions.

Carers who placed their spouse in care reported the greatest use of social support strategies and experienced the greatest degree of growth compared to those who live with their spouse. Internalising strategies did not contribute to predicted growth. Tedeschi & Calhoun (2004) argue that social support is important in facilitating growth and that self-disclosure of emotions over time in supportive social environments may facilitate cognitive processing and potential schema change leading to growth. A number of empirical studies report associations between social support and growth, most notably in emotional social support (Linley & Joseph, 2004; Weiss, 2004) rather than general social support. The importance of understanding the function of different types of social support has been highlighted through meta-analysis (Prati & Pietrantoni, 2009). These findings have implications for shaping dementia carer support groups over time.

3.5.5 Using the PTGI, BES and REQ with Spousal Dementia Carers

A number of low and cross loading items found in the data reduction analyses in the present study suggest the need for further qualitative research in assessing the use of these

questionnaires in the spousal dementia carer population and demonstrate that sub-scales reported in other populations may not be applicable in the present sample of spousal carers.

As outlined in section 3.2.4, socioemotional selectivity theory would suggest that emotion regulation strategies in older adults are used to maintain emotional well-being. Low loading items may be considered in this context (REQ: 'I harm or punish myself in some way', 'I do something energetic (e.g. play sport, go for a walk)', 'I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things)', 'Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream)'). Self-harm or harm to property are unlikely to meet emotional goals or be of benefit to carers with responsibility for a vulnerable spouse. Opportunities to undertake energetic outdoor activities or daydreaming may be less available for spousal dementia carers.

The nature of the spousal carer experience more generally may account for the low loading items on the PTGI ('I have a greater feeling of self-reliance', 'I am more willing to express my emotion', 'I know better that I can handle difficulties', 'I can better appreciate each day'). Carers may experience fear and uncertainty about their ability to cope with dementia progression and are reliant upon care professionals for support as dementia progresses which may impede feelings of self-reliance. Carers may not be enabled the time and space to better appreciate each day compared to life before taking on the role of carer and may experience the loss of mutual support and responsivity of their spouse to emotional expression. This may reduce willingness and motivation to express emotion in the spousal relationship and impede growth if there are limited socially supportive environments in which to express emotions.

3.5.6 Limitations of the study

3.5.6.1 Sampling

The present study was based on a sample drawn from a research register and is not, therefore, representative of all spousal dementia carers in Scotland more generally. There are many reasons for expressing interest in research and those who do so and then go on to participate may differ from those not targeted by the survey and from non-responders to the survey. Postal questionnaire responders in particular may represent higher socioeconomic status than non-responders (Tickle *et al.*, 2003). Less than a half of respondents who were offered the chance to participate in the current study took up the offer and, although a reasonable response to postal survey, it is unknown how this group may differ more generally from the broader spousal carer base in Scotland.

3.5.6.2 Small sample size and additional factors that may affect care transition analyses

The present study found that there are emotional consequences for spousal carers whose spouses had moved to care homes including higher levels of guilt, sadness, social support seeking, internalising and positive growth. Many factors have been implicated in the decision to place a spouse with dementia in care including severity of dementia (Bond & Clark, 2002), lack of social support (Bond *et al.*, 2003), higher socioeconomic status, older age (Gaugler *et al.*, 2003) and poorer physical health of the carer (De Frias *et al.*, 2005; Kiecolt-glaser *et al.*, 1991; Von Kanel *et al.*, 2012). We acknowledge the importance of these factors in the experience of caring for one's spouse with dementia and their possible role in care home placement although these factors were not recorded in the present study. It is not possible, therefore, to ascertain their association with care home placement, emotion regulation and positive growth.

The relatively smaller size of the groups of carers who had placed their spouse in care and who had experienced the death of their spouse, in comparison to participants living with their

spouse, may suggest caution in reading the results. In addition, due to small numbers, it was not possible to conduct more detailed statistical analysis, for example gender comparisons within two of the care transition groups (placed in care and experience death of spouse). Spouses who have placed their spouse in care and those who have experienced the death of their spouse with dementia may be an especially challenging group of carers to recruit into research. The results presented in this study, while based upon small samples, provide some interesting insights to be followed up.

3.5.6.3 Self-report and bias

The present results demonstrate a need for continued research to further develop tools for use in this population. There were no published studies in an older adult or carer population using either of the emotion questionnaires employed in the present study. All three questionnaires (REQ, BES and PTGI) relied upon self-report and therefore capture carers' perceptions of their emotional experiences, regulatory strategies and self-perceived growth at the time of survey. No objective measures were used to examine emotions or growth in the present study although the PTGI has been found to have inter-subjective validity between spouses (Weiss, 2002).

Published studies using the REQ and BES have not reported on biases that may exist, for example, on the social desirability of responses in the REQ and BES although the PTGI has been found to be independent of social desirability (Tedeschi & Calhoun, 1996; Wild & Paivio, 2002). The present study responses may, in part, be shaped by beliefs about what constitutes appropriate behaviour when caring for a vulnerable spouse with dementia.

3.5.6.4 Cross sectional research

As this study is cross-sectional it is not possible to comment definitively on the causal relationship between emotion regulation and personal growth or between care transition and

emotion regulation and positive growth. In addition, the present study did not examine the content and adaptive or maladaptive nature of particular emotion regulation strategies. It is not possible, therefore, to report on what it was about these strategies which may have facilitated growth.

As this is a retrospective study, carers were reliant upon long term memory when reporting emotion regulation and growth since taking on the role of carer. This has implications regarding the reliability of the study findings, including limited or reconstructed understanding of what has occurred and when (Jobe, Tourangeau & Smith, 1993), especially when recalling material which may be emotive in nature (Metts, Sprecher & Cupach, 1991). Questionnaire responses may be shaped by the timing of questionnaire completion on a particular day and may not capture the complexity of factors which shape emotional fluctuation more generally in this population.

The findings of the present study relate to the relative frequency of emotions experienced and it is not known whether and at what levels emotions impede carer adaptation or demonstrate a need for intervention and support. We concur with Joseph et al. (2012) that there is a need for longitudinal prospective studies which examine in detail the pattern of emotional state factors, appraisals, coping and post traumatic growth.

Despite these limitations, the present study was an important first step in exploring the emotional experience of spousal carers within a positive conceptual framework and the findings have a number of clinical implications which are outlined below.

3.5.7 Clinical Implications

In caring for a spouse with dementia, carers benefit from support to maintain their own psychological health although consideration of carers' needs may currently be taking place

in the absence of a positive conceptual framework. This study highlights the following issues for clinical practice:

- The use of a positive conceptual framework in clinical practice including screening for positive growth may promote understanding of positive aspects of spousal dementia care and positive care outcomes.
- Particular attention should be given to the simultaneous occurrence of positive and negative affect that can occur during spousal care.
- Persistent use of internalising strategies in the absence of constructive refocusing and social support seeking and in the presence of negative emotions such as guilt, sadness and fear and frustration may highlight support and intervention needs.
- Routine assessment of carers' emotional well-being may usefully include emotion profiling, the use of social support, and examination of the strategies used to manage the emotions experienced.
- Interventions that support carers to manage emotions including fear and frustration and encourage use of proactive emotion regulation strategies such as social support and constructive refocusing may enhance carer growth and support carers through care transition.

3.5.8 *Research recommendations*

Research is vital to inform the content and timing of psychological support and intervention for carers and to inform process and outcome evaluation. The results of the present study suggest the need for larger scale evaluations of concepts such as emotion regulation and PTG that have been ignored in spousal dementia care to date. Research priorities should include the examination of the experience of emotions in dementia carers and how these are managed within a positive framework, including awareness of emotions experienced; factors

that enable carers to manage their emotions; and availability, uptake and use of social support.

Future research will usefully incorporate longitudinal methods to further understand the experience of spousal carers and comparison groups matched in age, gender and marital status, over time. Consideration should be given to developing compassionate methods to recruit carers who are hard to reach, including those who have experienced care home placement or death of their spouse. There may be a role for qualitative and quantitative methods to capture the range of emotions, regulation strategies and growth that are experienced over time and in different contexts and how these interact with other variables involved in dementia care over time.

3.6 CONCLUSIONS

The present study found evidence of positive growth in spousal dementia carers, as demonstrated using the Post Traumatic Growth Inventory (PTGI), and evidences that carers experience a range of positive and negative emotions as they care for their spouse. Findings highlight the need for further exploration into emotion regulation and PTG with this population. Redressing the research balance using a positive conceptual framework may afford researchers an opportunity to look at positive as well as negative emotional consequences of caring for someone with dementia and the way in which emotional consequences are managed.

Conflict of interest

None

Acknowledgements

We would like to thank each individual who give their time to participate in this study and enable this research to happen. Thanks also to Dr Nuno Ferreira for guidance on statistical analysis, Phil Brown at the Scottish Dementia Clinical Research Network for facilitating access to the research register, and Hasnain Sheikh, sub postmaster at Warriston Post Office, for processing postal questionnaires.

REFERENCES

- Adams, K. B., McClendon, M. J., & Smyth, K. A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7, 301–319.
- Aldao, A., Nolen-Hoeksema, S., Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review*, 30, 217–237.
- Aldwin, C.M., & Levenson, M.R. (2004). Posttraumatic growth: A developmental perspective. *Psychological Inquiry*, 15, 19–21.
- Anderson, W. P., & Lopez-Baez, S. I. (2008). Measuring growth with the Posttraumatic Growth Inventory. *Measurement and Evaluation in Counseling and Development*, 40, 215–227.
- Baikie, E., (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, 17, 289–299.
- Bargh, J. A., & Williams, L. E. (2007). The non-conscious regulation of emotion. In J. J. Gross (Ed.) *Handbook of emotion regulation*. The Guildford Press. New York: London.
- Bedard, M., Kuzik, R., Chambers, L. D., Molloy, W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: the contribution of care-recipient problem behaviors. *International Psychogeriatrics*, 17, 99–118.
- Blanchard-Fields, F. (2007). Everyday problem solving and emotion: An adult developmental perspective. *Current Directions in Psychological Science*, 16, 26–31.

Blieszner, R., & Shiflett, P. A. (1990). The effects of Alzheimer's disease on close relationships between patients and caregivers. *Family Relations*, 39, 57–62.

Boss, P. (2011). *Loving someone who has dementia: how to find hope while coping with stress and grief*. United States of America. Jossey-Bass.

Bond, M.J., & Clark, M.S. (2002). Predictors of the decision to yield care of a person with dementia. *Australasian Journal on Ageing*, 21, 86–91.

Bond, M. J., Clark, M. S., & Davies, S. (2003). The quality of life of spouse dementia caregivers: Changes associated with yielding to formal care and widowhood. *Social Science and Medicine*, 57, 2385–2395.

Boyraz, G., & Efstathiou, N. (2011). Self-Focused Attention, Meaning, and Posttraumatic Growth: The Mediating Role of Positive and Negative Affect for Bereaved Women. *Journal of Loss and Trauma: International Perspectives on Stress & Coping*, 13–32.

Bramble, M., Moyle, W., & Margaret McAllister, M. (2009). Long-term care. Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing*, 3118–3125.

Braun, M., Bailey, B., Perren, S., Hornunga, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective *Aging & Mental Health*, 13, 426–436.

Bromley, D. B. (1990). *Behavioral gerontology: central issues in the psychology of ageing*. Chichester: John Wiley.

Campbell-Sills, L. , Barlow, D. H., Brown, T. A., & Hoffmann, S. G. (2006). Effects of suppression and acceptance on emotional responses of individuals with anxiety and mood disorders. *Behaviour Research and Therapy*, 44, 1251–1263.

Campbell-Sills, L., & Barlow, D. H. (2007). Incorporating emotion regulation into conceptualizations and treatments of anxiety and mood disorders. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 542–559). The Guildford Press. New York: London.

Carolan, L. A., & Power, M. J. (2011). Special issue article: what basic emotions are experienced in bipolar disorder? *Clinical Psychology & Psychotherapy*, 18, 366–378.

Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science*, 312, 1913–1915.

Carstensen, L. L., Isaacowitz, D. M., Charles, S. T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist*, 54, 165–181.

Carstensen, L. L. Turan, B., Scheibe, S., Ram, N., Ersner-Hershfield, H., Samanez-Larkin, G. R., Brooks, K. P., Nesselroade, J. R. (2011). Emotional experience improves with age: evidence based on over 10 years of experience sampling. *Psychology and Aging*, 26, 21–33.

Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research*, 1, 245–276.

Chambers, R., Gullone, E., Allen, N. B. (2009). Mindful emotion regulation: An integrative review, 29, *Clinical Psychology Review*, 560–572.

Charles, S. T. (2010). Strength and vulnerability integration: a model of emotional well-being across adulthood, *Psychological Bulletin*, 136, 1068–1091.

Charles, S. T., & Carstensen, L. L. (2007). Emotion regulation and aging. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 307–330). The Guildford Press. New York: London.

Cohen, J. (1992). Quantitative methods in psychology: A power primer. *Psychological Bulletin*, 112, 155–159.

Collins, C., & Jones, R. (1997). Emotional distress and morbidity in dementia carers: a matched comparison of husbands and wives. *International Journal of Geriatric Psychiatry*, 12, 1168–1173.

Comrey, A. L., & Lee, H. B. (1992). *A first course in factor analysis*. (2nd Edition). Hillsdale, NJ: Erlbaum.

- Cooper, C., Balamurali, T. B. S. & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics*, 19, 175–195.
- Cooper, C., Katona, C., Orrell, M., Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929–936.
- Costello, A. B., & Osborne, J. W. (2005). Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment, Research and Evaluation*, 10, 1–9.
- Croog, S. H., Burleson, J. A., Sudilovsky, A., Baume, R. M (2006). Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging & Mental Health*, 10, 87–100.
- De Frias, C. M., Tuokko, H., & Rosenberg, T. (2005). Caregiver physical and mental health predicts reactions to caregiving. *Aging & Mental Health*, 9, 331–336.
- De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J. & Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry*, 18, 149–154.
- Ehring, T., Fischer, S., Schnulle, J., Bösterling, A., & Tuschen-Caffier, B. (2008). Characteristics of emotion regulation in recovered depressed versus never depressed individuals. *Personality and Individual Differences*, 44, 1574–1584.
- Eloniemi-Sulkava, U., Notkola, I. L., Hamalainen, K., Rahkonen, T., Viramo, P., Hentinen, M. (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics*, 14, 47–58.
- Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research: Linking research with practice*, 13, 106–125.

- Fabrigar, L. R., Wegener, D. T., MacCallum, R. C., & Strahan, E. J. (1999). Evaluating the use of exploratory factor analysis in psychological research. *Psychological Methods*, 4, 272–299.
- Fehlinger, T., Stumpfenhorst, M., Stenzel, N., & Rief, W. (2013). Emotion regulation is the essential skill for improving depressive symptoms. *Journal of Affective Disorders*, 144, 116–122.
- Field, A. (2013). *Discovering statistics using IBM SPSS Statistics* (4th Edition). SAGE publications Ltd.
- Finch, J. (1995). Responsibilities, obligations and commitments. In I. Allen & E. Perkins (Eds.) *The future of family care for older people*. London: HMSO.
- Finucane, A. M., Dima, A., Ferreira, N., Halvorsen, M. (2012). Basic emotion profiles in healthy, chronic pain, depressed and PTSD individuals. *Clinical Psychology & Psychotherapy*, 19, 14–24.
- Fox, J. R. E., & Froom, K. (2009). Eating Disorders: A Basic Emotion Perspective. *Clinical Psychology and Psychotherapy*, 16, 328–335.
- Fox, R. E., Smithson, E., Baillie, S., Nuno Ferreira, N., Mayr, I., & Power, M. J. (2012). Emotion Coupling and Regulation in Anorexia Nervosa. *Clinical Psychology and Psychotherapy*, 20, 319–333.
- Gangstad, B., Norman, P., & Barton, P. J (2009). Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology*, 54, 69–75.
- Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Predicting institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, 43, 219–229.
- Gonyea, J. G., Parisa, R., & de Saxe Zerdena, L. (2008). Adult daughters and aging mothers: The role of guilt in the experience of caregiver burden. *Aging & Mental Health*, 12, 559–567.

Gonzalez, E. W., Polansky, M., Lippa, C. F., Walker, D., & Feng, D. (2011). Family Caregivers At Risk: Who Are They? *Issues in Mental Health Nursing*, 32, 528–536.

Graham, S. M., Huang, J. Y., Clark, M. S., & Helgeson, V. S. (2008). The Positives of Negative Emotions: Willingness to Express Negative Emotions Promotes Relationships. *Personality and Social Psychology Bulletin*, 34, 394-406.

Grazt, K. L. & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of Psychopathology and Behavioral Assessment*, 26, 41–54.

Gross, J. J. (1999). Emotion Regulation: Past, Present, Future. *Cognition and Emotion*, 13, 551–573.

Gross, J. J. & John, O. P. (2002). Wise emotion regulation. In L. F. Barrett & P. Salovey (Eds.) *The wisdom of feelings: Psychological processes in emotional intelligence* (pp. 297-318). New York: Guildford Press.

Gross, J. J., & John, O.P. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. *Journal of Personality and Social Psychology*, 85, 348–362.

Gross, J. J., & Munoz, R. F. (1995). Emotion Regulation and Mental Health. *Clinical Psychology: Science and Practice*, 2, 151–164.

Gross, J. J., & Thomson, R. A. (2007). Emotion regulation: conceptual foundations. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 3–26). The Guildford Press. New York: London.

Harre, R. (1986). An outline of the social constructionist viewpoint. In R. Harre (Ed.) *The social construction of emotions* (pp. 2–14). Oxford, England: Basil Blackwell.

Hayley, W., Levine, E. G., Brown, S. L., Berry, J. W., & Hughes, G. H. (1987). Psychological, social and health consequences of caring for a relative with senile dementia. *Journal of the American Geriatrics Society*, 35, 405–411.

Hayley, W., & Pardo, K. M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging*, 4, 389–392.

Hennings, J., Froggatt, K., & Payne, S. (2013). Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study. *Palliative Medicine*, 0, 1–9.

Hicks, J. A., Trent, J., Davis, W. E., King, L. A. (2012). Positive affect, meaning in life, and future time perspective: An application of socioemotional selectivity theory. *Psychology and Aging*, 27, 181–189.

Ho, S. M. Y., Chan, C. L. W., & Ho, R. T. H. (2004). Posttraumatic growth in chinese cancer survivors. *Psycho-Oncology*, 13, 377–389.

Jansson, W., Nordberg, G., Grafström, M. (2001). Patterns of elderly spousal caregiving in dementia care: an observational study, *Journal of Advanced Nursing*, 34, 804–812.

Jobe, J. B., Tourangeau, R., & Smith, A. F. (1993). Contributions of survey research to the understanding of memory. *Applied Cognitive Psychology*, 7, 567–584.

John, O. P., & Gross, J. J. (2007). Individual differences in emotion regulation. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 351–372). The Guildford Press. New York: London.

Joling, K.J., Hout, H.P.J. van, Schellevis, F.G., Horst, H. E. van der, Scheltens, P., Marwijk, H.W.J. van (2010). Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *American Journal of Geriatric Psychiatry*, 18, 146–153.

Joseph, S., & Linley, P.A. (2006). Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, 26, 1041–1053.

- Joseph, S., Murphy, D., Regel, S. (2012). Special Issue Article An affective–cognitive processing model of post-traumatic growth. *Clinical Psychology and Psychotherapy*, 19, 316–325.
- Kiecolt-glaser, J. K., Dura, J. R., Speicher, C. E., Trask, J., & Glaser, R. (1991). Spousal Caregivers of Dementia Victims: Longitudinal Changes in Immunity and Health. *Psychosomatic Medicine*, 53, 345–362.
- Kim, Y., Carver, C., Deci, E., Kasser, T. (2008). Adult attachment and psychological wellbeing in cancer caregivers: the meditational role of spouses' motives for care giving. *Health Psychology*, 27, 8144–8154.
- Kim, Y., & Schulz, R. (2008). Family Caregivers' Strains : Comparative Analysis of Cancer Caregiving With Dementia, Diabetes, and Frail Elderly Caregiving. *Journal of Aging and Health*, 20, 483–503.
- Laidlaw, K., & Thompson, L. W. (2008). Cognitive behaviour therapy with depressed older people. In K. Laidlaw & B. Knight (Eds.) *Handbook of emotional disorders in later life: assessment and treatment*. Oxford University Press.
- Lindgren, C. L., Connelly, C. T., Gaspar, H. L. (1999). Grief in Spouse and Children Caregivers of Dementia Patients. *Western Journal of Nursing Research*, 21, 521–537.
- Linley, P. A., & Joseph, S. (2004). Positive Change Following Trauma and Adversity: A Review. *Journal of Traumatic Stress*, 17, 11–21.
- Linley, P. A., Andrews, L., & Joseph, S. (2007). Confirmatory Factor Analysis of the Posttraumatic Growth Inventory. *Journal of Loss and Trauma: International Perspectives on Stress & Coping*, 12, 321 – 332.
- Livingstone, K., Harper, S., Gillanders, D. (2009). An exploration of emotion regulation in psychosis. *Clinical Psychology & Psychotherapy*, 16, 418–430.
- Lopes, P. N., Salovey, P., Cote, S., & Beers, M. (2005). Emotion regulation abilities and the quality of social interaction. *Emotion*, 5, 113–118.

- Lundh, U., Sandberg, J., Nolan, M. (2000). 'I don't have any other choice': spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32, 1178–1186.
- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological methods*, 4, 84–99.
- Magai, C., Consedine, N. S., Krivoshekova, Y. S., Kudadjie-Gyamfi, E., McPherson, R. (2006). Emotion experience and expression across the adult life span: Insights from a multimodal assessment study. *Psychology and Aging*, 21, 303–317.
- Marroquin, B. (2011). Interpersonal emotion regulation as a mechanism of social support in depression. *Clinical Psychology Review*, 31, 1276–1290.
- Martin, M., Peter-Wight, M., Braun, M., Hornung, R., & Scholz, U. (2009). The 3-phase-model of dyadic adaptation to dementia: why it might sometimes be better to be worse. *European Journal of Ageing*, 6, 291–301.
- Mauss, I. B., Bunge, S. A., & Gross, J. J. (2007). Automatic Emotion Regulation. *Social and Personality Psychology Compass*, 1, 146–167.
- McCausland, J., & Pakenham, K. I. (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 15, 853–869.
- McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, 7, 81–91.
- Mclennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15, 522–530.
- Metts, S., Sprecher, & Cupach (1991). Retrospective self-reports. In B. M. Montgomery & A. Duck (Eds). *Studying Interpersonal Interaction* (pp. 162–175). The Guildford Press.

- Meuser, T.M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41, 658–670.
- Morrill, E., F., Brewer, N. T., O'Neill, Lillie, S. E., Dees, E. C., Carey, L. A. Rimer, B. K. (2008). The interaction of post-traumatic growth and post-traumatic stress symptoms in predicting depressive symptoms and quality of life. *Psycho-Oncology*, 17, 948–953.
- Morris, L.W., Morris, R.G., & Britton, P.G, (1989). Cognitive style and perceived control in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 62, 173–179.
- Nolan & Dellasega, (2000). 'I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, 31, 759–767.
- Nolen-Hoeksema, S., & Aldao, A. (2011). Gender and age differences in emotion regulation strategies and their relationship to depressive symptoms. *Personality and Individual Differences*, 51, 704–708.
- Ochsner, K. N., & Gross, J. J. (2004). Thinking makes it so: a social cognitive neuroscience approach to emotion regulation. In R. F. Baumeister & K. D. Vohs (Eds.) *Handbook of self-regulation: Research, theory and applications* (pp. 229–255). New York: Guildford Press.
- Orgeta, V. (2009). Specificity of age differences in emotion regulation. *Aging & Mental Health*, 13, 818–826.
- O'Shaughnessy, M., Lee, K., Lintern, T. (2010). Changes in the couple relationship in dementia care: spouse carers' experiences. *Dementia*, 9, 237–258.
- Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's Disease and related dementias. *The Gerontologist*, 47, 798–809.
- Oyebode, J. (2003). Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, 9, 45–53.

- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behaviour*, 19, 2–21.
- Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health*, 10, 539–548.
- Perry, J., & O'Connor, D. (2002). Preserving personhood: (Re)Membering the spouse with dementia. *Family Relations*, 51, 55–61.
- Phillips, K. F. V., & Power, M. J. (2007). A new self-report measure of emotion regulation in adolescents: The Regulation of Emotions Questionnaire. *Clinical Psychology and Psychotherapy*, 14, 145–156.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological and Social Sciences*, 62, 126–137.
- Pinquart, M., & Sörensen, S. (2011). Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults: A Meta-Analytic Comparison. *Psychology and Aging*, 26, 1–14.
- Plutchik, R. (1980). *Emotion: A psychoevolutionary synthesis*. New York: Harper & Row.
- Power, M.J. (2006). The structure of emotion: An empirical comparison of six models. *Cognition and Emotion*, 20, 694–713.
- Power, M. J., & Tarsia, M. (2007). Basic and complex emotions in depression and anxiety. *Clinical Psychology and Psychotherapy*, 14, 19–31.
- Prati, G., & Pietrantonio, L. (2009). Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: A meta-analysis. *Journal of Loss and Trauma*, 14, 364–388.
- Pruchno, R. A., & Resch, N. L. (1989). Aberrant behaviors and Alzheimer's Disease: Mental health effects on spouse caregivers. *Journal of Gerontology: Social Sciences*, 44, 177–182.

- Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health*, 13, 143–154.
- Riordan J. M., Bennett A. V. (1998). An evaluation of an augmented domiciliary service to older people with dementia and their carers. *Aging and Mental Health*, 2, 137–143.
- Roach, L., Laidlaw, K., Gillanders, D., Quinn, K. (2013). Validation of the Caregiver Guilt Questionnaire (CGQ) in a sample of British dementia caregivers. (in submission). *International Psychogeriatrics*.
- Robinson, K. M., Adkisson, P., & Weinrich, S. (2001). Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease. *Journal of Advanced Nursing*, 36, 573–582.
- Rudd, M. G., Viney, L. L., & Preston, C. A (1999). The Grief Experienced by Spousal Caregivers of Dementia Patients: the Role of Place of Care of Patient and Gender of Caregiver. *The International Journal of Aging and Human Development*, 48, 217–240.
- Ryan, A. and Scullion, H. (2000). Nursing home placement: an exploration of the experience of family carers. *Journal of Advanced Nursing*, 32, 1187–1195.
- Sanders, S., Ott, C. H., Kelber, S. (2008). The Experience of high levels of grief in caregivers of persons with Alzheimer's disease. *Death Studies*, 31, 495–523.
- Scarff, S., & Zultner, A. (2012). *Dementia: the journey ahead - a practical guide for in-home caregivers*. Langdon Street Press.
- Scheibe, S., & Carstensen, L. L. (2010). Emotional Aging: Recent Findings and Future Trends. *Journal of Gerontology: Psychological Sciences*, 65, 135–144.
- Scheibe, S., & Blanchard-Fields, F. (2009). Effects of regulating emotions on cognitive performance: What is costly for young adults is not so costly for older adults. *Psychology and Aging*, 24, 217–223.

Schore, A. N. (2003). *Affect regulation and the repair of the self*. New York: W. W. Norton & Company, Inc.

Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961–967.

Searson, R., Hendry, A.M., Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging & Mental Health*, 12, 276–282.

Şenol-Durak, E., & Ayvaşık, H. B. (2010). Factors associated with posttraumatic growth among the spouses of myocardial infarction patients. *Journal of Health Psychology*, 15, 5–95.

Sheikh, A. I., & Marotta, S. A. (2005). A cross-validation study of the posttraumatic growth inventory. *Measurement and Evaluation in Counseling and Development*, 38, 66–77.

Spaid, W.M., & Barusch, A.S. (1994). Emotional closeness and caregiver burden in marital relationship. *Journal of Gerontological Social Work*, 21, 197–211.

Stevens, J. P. (2009). *Applied multivariate statistics for the social sciences*. (5th Edition) New York: Routledge.

Szasz, P. L., Szentagotai, A. & Hofmann, S. G. (2011). The effect of emotion regulation strategies on anger. *Behaviour Research and Therapy*, 49, 114–119.

Tabachnick, B. G., & Fidell, L. S. (2007). *A Practical Approach to using Multivariate Analyses Using Multivariate Statistics* (6th edition). Boston: Pearson Education.

Taku, K., Cann, A. C., Calhoun, L. G., & Tedeschi, R. G. (2008). The factor structure of the posttraumatic growth inventory: A comparison of five models using confirmatory factor analysis. *Journal of Traumatic Stress*, 21, 158–164.

- Tamres, L. K., Janicki, D., & Helgeson, V. S. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review*, 6, 2–30.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455–471.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological Inquiry* 15, 1–18.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (Eds.). (1998). *Posttraumatic growth: Positive changes in the aftermath of crisis*. Mahwah, NJ: Erlbaum.
- Tickle, M., Milsom, K. M., Blinkhorn, A. S., & Worthington, H. V. (2003). Comparing different methods to detect and correct nonresponse bias in postal questionnaire studies. *Journal of Public Health Dentistry*, 63, 112–118.
- Tilse, C. (1998). Continuing or refusing to care: The meaning of placing a spouse in long term care. *American Journal of Alzheimer's Disease*, 13, 29–33.
- Tugade, M. M., Fredrickson, B. L. (2004). Resilient Individuals Use Positive Emotions to Bounce Back From Negative Emotional Experiences. *Journal of Personality and Social Psychology*, 86, 320–333.
- Tweedy, M. P., & Guarnaccia, C. A. (2007). Change in depression of spousal caregivers of dementia patients following patient's death. *Omega: Journal of Death and Dying*, 56, 217–228.
- Vishnevsky, T., Cann, A., Calhoun, L. G., Tedeschi, R. G., & Demakis, G. J. (2010). Gender differences in self-reported posttraumatic growth: a meta-analysis. *Psychology of Women quarterly*, 34, 110–120.
- Von Kanel, R., Mausbach, B. T., Dimsdale, J. E., Mills, P. J., Patterson, T. L., Ancoli-israel, S., Ziegler, M. G., Roepke, S. K., Chattillion, E. A., Allison, M., & Grant, I. (2012). Effect

of chronic dementia caregiving and major transitions in the caregiving situation on kidney function: a longitudinal study. *Psychosomatic Medicine*, 74, 214–220.

Weiss, T. (2002). Posttraumatic growth in women with breast cancer and their husbands: an inter-subjective validation study. *Journal of Psychosocial Oncology*, 65–80.

Weiss, T. (2004). Correlates of posttraumatic growth in married breast cancer survivors. *Journal of Social and Clinical Psychology*, 23, 733–746.

Wild, N. D., & Paivio, S. C., (2002). Psychological adjustment, coping, and emotion regulation as predictors of posttraumatic growth. *Journal of Aggression, Maltreatment & Trauma*, 97–122.

Wright, F. (1998). *Continuing to care: the effect on spouses and children of an older person's admission to a care home*. Joseph Rowntree Foundation.

Zoeller, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review*, 26, 626–653.

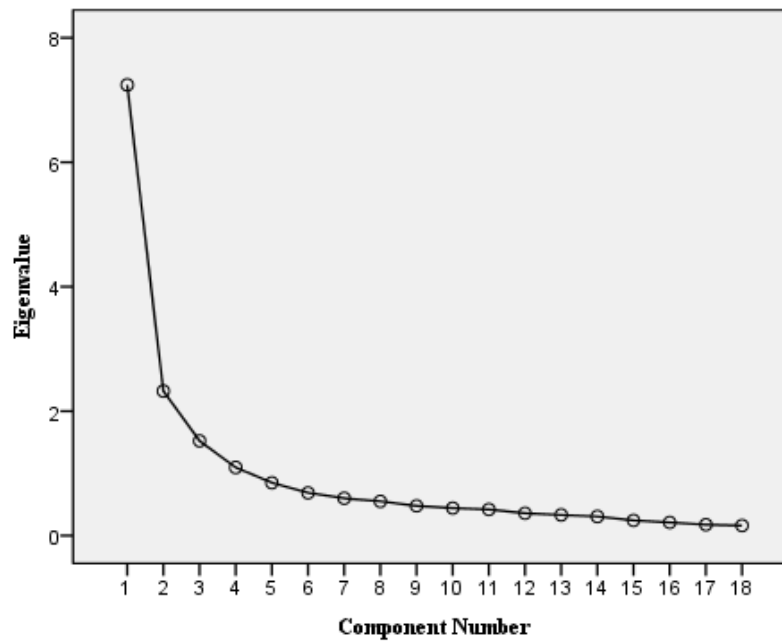
Appendix 1. Figure 3. Scree plot of BES factors

Table 13. Correlations between BES Factors: Factor correlation matrix

Factor	1	2	3	4
BES Factor 1				
BES Factor 2	.57			
BES Factor 3	.46	.56		
BES Factor 4	-.12	-.26	-.06	

Appendix 2. Figure 4. Scree plot of REQ factors

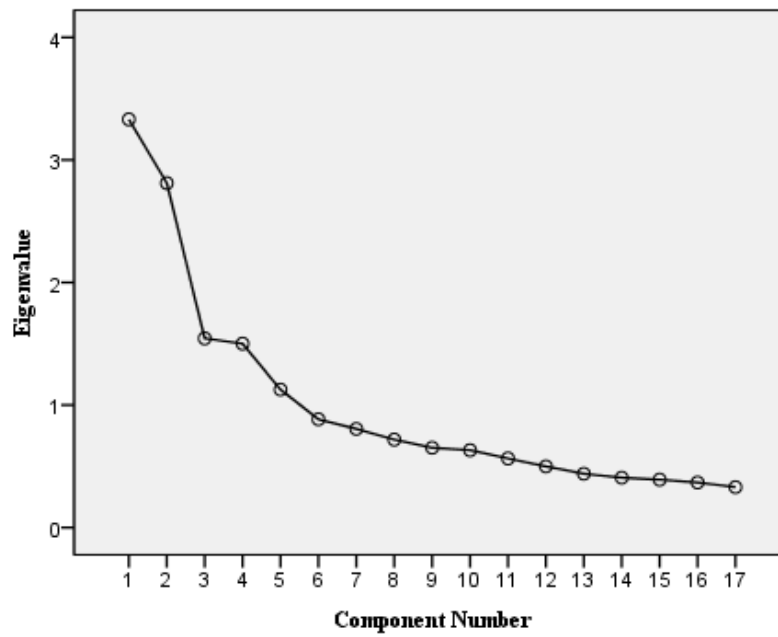


Table 14. Correlations between REQ Factors: Factor correlation matrix

Factor	1	2	3	4
REQ Factor 1				
REQ Factor 2	.13			
REQ Factor 3	-.05	.21		
REQ Factor 4	.22	-.09	-.19	

Appendix 3. Figure 5. Scree plot of PTGI factors

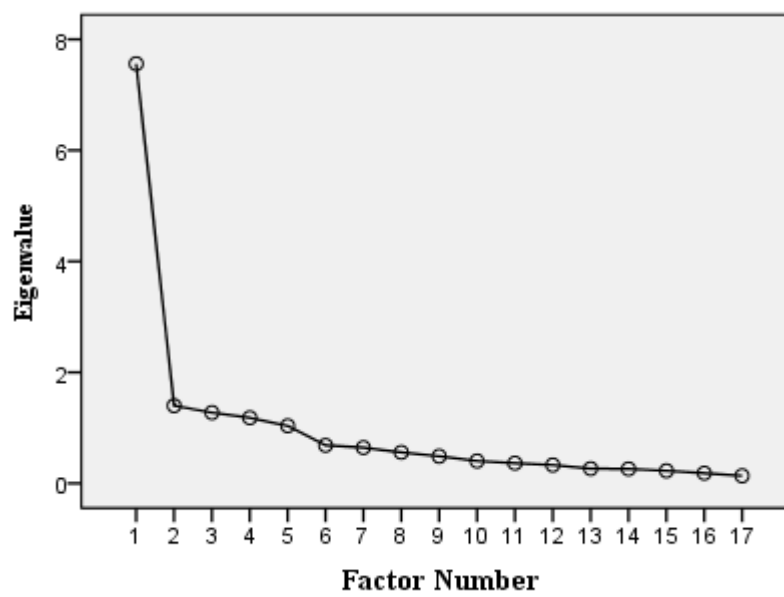


Table 15. Correlations between PTGI Factors: Factor correlation matrix

Factors	1	2	3	4	5
PTGI Factor 1					
PTGI Factor 2	.51				
PTGI Factor 3	.49	.43			
PTGI Factor 4	.44	.39	.39		
PTGI Factor 5	.43	.38	.38	.37	

APPENDIX 3 Thesis Folio References

- Ablitt, A., Jones, G. V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health*, 13, 497–511.
- Adams, K. B., McClendon, M. J., & Smyth, K. A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7, 301–319.
- Akpinar, B., Kucukguc, O., & Yener, G. (2011). Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship*, 43, 248–254.
- Aldao, A., Nolen-Hoeksema, S., Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review*, 30, 217–237.
- Aldwin, C.M., & Levenson, M.R. (2004). Posttraumatic growth: A developmental perspective. *Psychological Inquiry*, 15, 19–21.
- Amico, K. R. (2009). Percent Total Attrition: A poor metric for study rigor in hosted intervention designs. *American Journal of Public Health*, 99, 1567–1575.
- Anderson, W. P., & Lopez-Baez, S. I. (2008). Measuring growth with the Posttraumatic Growth Inventory. *Measurement and Evaluation in Counseling and Development*, 40, 215–227.
- Ankri, J., Andrieu, S., Beaufils, B., Grand, A., Henrard, J. C. (2005). Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. *International Journal of Geriatric Psychiatry*, 20, 254–260.
- Arean, P. A., Miranda, J. (1997). The utility of the Center for Epidemiological Studies: Depression Scale in older primary care patients. *Aging & Mental Health*, 1, 147–156.
- Baikie, E., (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, 17, 289–299.
- Bargh, J. A., & Williams, L. E. (2007). The nonconscious regulation of emotion. In J. J. Gross (Ed.) *Handbook of emotion regulation*. The Guildford Press. New York: London.

- Barusch, A. S., & Spaid, W. M. (1989). Gender differences in caregiving: why do wives report greater burden? *The Gerontologist*, 29, 667–676.
- Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging*, 15, 259–271.
- Bedard, M., Kuzik, R., Chambers, L. D., Molloy, W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: the contribution of care-recipient problem behaviors. *International Psychogeriatrics*, 17, 99–118.
- Black, W. & Almeida, O. P. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, 16, 295–315.
- Blanchard-Fields, F. (2007). Everyday problem solving and emotion: An adult developmental perspective. *Current Directions in Psychological Science*, 16, 26–31.
- Blieszner, R., & Shifflett, P. A. (1990). The effects of Alzheimer's disease on close relationships between patients and caregivers. *Family Relations*, 39, 57–62.
- Bond, M.J., & Clark, M.S. (2002). Predictors of the decision to yield care of a person with dementia. *Australasian Journal on Ageing*, 21, 86–91.
- Bond, M. J., Clark, M. S., & Davies, S. (2003). The quality of life of spouse dementia caregivers: Changes associated with yielding to formal care and widowhood. *Social Science and Medicine*, 57, 2385–2395.
- Boss, P. (2011). *Loving someone who has dementia: how to find hope while coping with stress and grief*. United States of America. Jossey-Bass.
- Boyraz, G., & Efstathiou, N. (2011). Self-Focused Attention, Meaning, and Posttraumatic Growth: The Mediating Role of Positive and Negative Affect for Bereaved Women. *Journal of Loss and Trauma: International Perspectives on Stress & Coping*, 13–32.

- Bramble, M., Moyle, W., & Margaret McAllister, M. (2009). Long-term care. Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing*, 3118–3125.
- Braun, M., Bailey, B., Perren, S., Hornunga, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: A dyadic perspective *Aging & Mental Health*, 13, 426–436.
- Brink, T. L., Yesavage, J. A., Lum, O., Heersema, P., Adey, M. (1982). Screening tests for geriatric depression. *Clinical Gerontologist*, 1, 37–44.
- Bromley, D. B. (1990). *Behavioral gerontology: central issues in the psychology of ageing*. Chichester: John Wiley.
- Brown-Wilson, C., & Davies, S. (2009). Providing quality care: Developing relationships in long term care environments: the contribution of staff. *Journal of Clinical Nursing*, 18, 1746–1755.
- Burns, A., Lawlor, B., & Craig, S. (2002). Rating scales in old age psychiatry. *British Journal of Psychiatry*, 180, 161–167.
- Burton, C. A., & Sistler, A. B. (1996). A note on whether spousal dementia carers try to control their environment or themselves. *The Journal of Psychology*, 130, 421–427.
- Campbell-Sills, L. , Barlow, D. H., Brown, T. A., & Hoffmann, S. G. (2006). Effects of suppression and acceptance on emotional responses of individuals with anxiety and mood disorders. *Behaviour Research and Therapy*, 44, 1251–1263.
- Campbell-Sills, L., & Barlow, D. H. (2007). Incorporating emotion regulation into conceptualizations and treatments of anxiety and mood disorders. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 542–559). The Guildford Press. New York: London.
- Cann, A., Calhoun, L. G., Tedeschia, R. G., Ryan P., Kilmera, R. P., Gil-Rivasa, V., Vishnevskya, T., & Danhauerb, S. C. (2010). The Core Beliefs Inventory: a brief measure of disruption in the assumptive world. *Anxiety, Stress & Coping: An International Journal*, 23, 19–34.

- Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in Dementia. *Dementia*, 9, 327–353.
- Carolan, L. A., & Power, M. J. (2011). Special issue article: what basic emotions are experienced in bipolar disorder? *Clinical Psychology & Psychotherapy*, 18, 366–378.
- Carstensen, L. L. (2006). The influence of a sense of time on human development. *Science*, 312, 1913–1915.
- Carstensen, L. L., Isaacowitz, D. M., Charles, S. T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist*, 54, 165–181.
- Carstensen, L. L., Turan, B., Scheibe, S., Ram, N., Ersner-Hershfield, H., Samanez-Larkin, G. R., Brooks, K. P., Nesselroade, J. R. (2011). Emotional experience improves with age: evidence based on over 10 years of experience sampling. *Psychology and Aging*, 26, 21–33.
- Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate Behavioral Research*, 1, 245–276.
- Chambers, R., Gullone, E., Allen, N. B. (2009). Mindful emotion regulation: An integrative review, 29, *Clinical Psychology Review*, 560–572.
- Charles, S. T. (2010). Strength and vulnerability integration: a model of emotional well-being across adulthood, *Psychological Bulletin*, 136, 1068–1091.
- Charles, S. T., & Carstensen, L. L. (2007). Emotion regulation and aging. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 307–330). The Guildford Press. New York: London.
- Chenoworth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontologist*, 26, 267–272.
- Clark, M. S., Bond, M. J. (1995). The Adelaide Activities Profile: a measure of lifestyle activities of the elderly. *Aging: Clinical and Experimental Research*, 7, 174–184.

- Clark, M. S., Bond, M. J. (2000). The effect on lifestyle activities of caring for a person with dementia. *Psychology, Health & Medicine*, 5, 13–27.
- Clark, M. S., Bond, M. J., & Hecker, J. R. (2007). Environmental stress, psychological stress and allostatic load. *Psychology Health & Medicine*, 12, 18–30.
- Cohen, J. (1992). Quantitative methods in psychology: A power primer. *Psychological Bulletin*, 112, 155–159.
- Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 386–396.
- Collins, C., & Jones, R. (1997). Emotional distress and morbidity in dementia carers: a matched comparison of husbands and wives. *International Journal of Geriatric Psychiatry*, 12, 1168–1173.
- Comrey, A. L., & Lee, H. B. (1992). *A first course in factor analysis*. (2nd Edition). Hillsdale, NJ: Erlbaum.
- Connell, C. M., Janevic, M. R., & Gallant, M. P. (2001). The Costs of Caring: Impact of Dementia on Family Caregivers. *Journal of Geriatric Psychiatry and Neurology*, 14, 179–187.
- Cooper, C., Balamurali, T. B. S. & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics*, 19, 175–195.
- Cooper, C., Katona, C., Orrell, M., Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 23, 929–936.
- Coppel, D. B., Burton, C., Becker, J., & Fiore, J. (1985). Relationships of cognitions associated with coping reactions to depression in spousal caregivers of Alzheimer's disease patients. *Cognitive Therapy and Research*, 9, 253–266.

- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology, 20*, 176–185.
- Costello, A. B., & Osborne, J. W. (2005). Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical Assessment, Research and Evaluation, 10*, 1–9.
- Croog, S. H., Burleson, J. A., Sudilovsky, A., Baume, R. M (2006). Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging & Mental Health, 10*, 87–100.
- Cuijpers, (2005). Depressive disorders in caregivers of dementia patients: A systematic Review. *Aging & Mental Health, 9*, 325–330.
- Currier, J. M., Mallot, J., Martinez, T. E, Sandy, C., & Neimeyer, R. A. (2013). Bereavement, religion, and posttraumatic growth: A matched control group investigation. *Psychology of Religion and Spirituality, 5*, 69–77.
- Davidson, R. J., Jackson, D. C., Kalin, N. H. (2000). Emotion, plasticity, context, and regulation: Perspectives from affective neuroscience. *Psychological Bulletin, 126*, 890–909.
- Davies, S., & Nolan, M. (2006). ‘Making it better’: Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies, 43*, 281–291.
- De Frias, C. M., Tuokko, H., & Rosenberg, T. (2005). Caregiver physical and mental health predicts reactions to caregiving. *Aging & Mental Health, 9*, 331–336.
- De Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I., Jolles, J. & Verhey, F. R. J. (2003). Behavioural disturbances in dementia patients and quality of the marital relationship. *International Journal of Geriatric Psychiatry, 18*, 149–154.

- Dougall, A. L. & Baum, A. (2012). Stress, health and illness. In A. Baum, A. A. Tracey, J. S. Revenson (Eds.) *Handbook of Health Psychology* (2nd Edition, pp. 53–78). Taylor & Francis Group.
- Drentea, P., Clay, O. J., Roth, D. L., & Mittelman, M. S. (2006). Predictors of improvement in social support: Five years effects of structured intervention for caregivers of spouse with Alzheimer's disease. *Social Science and Medicine*, 63, 957–967.
- Dura, J. R., Haywood-Niler, E., & Kiecolt-Glaser, J. K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's Disease dementia: A preliminary comparison. *The Gerontologist*, 30, 332–36.
- Edmonds, S., & Hooker, K. (1992). Perceived Changes in Life Meaning Following Bereavement. *OMEGA: Journal of Death and Dying*, 25, 307–318.
- Ehring, T., Fischer, S., Schnulle, J., Bösterling, A., & Tuschen-Caffier, B. (2008). Characteristics of emotion regulation in recovered depressed versus never depressed individuals. *Personality and Individual Differences*, 44, 1574–1584.
- Eloniemi-Sulkava, U., Notkola, I. L., Hamalainen, K., Rahkonen, T., Viramo, P., Hentinen, M. (2002). Spouse caregivers' perceptions of influence of dementia on marriage. *International Psychogeriatrics*, 14, 47–58.
- Elvish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research: Linking research with practice*, 13, 106–125.
- Epstein-Lubow, G., Davis, J. D., Miller, I. W., & Tremont, G. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, 21, 198–203.
- Fabrigar, L. R., Wegener, D. T., MacCallum, R. C., & Strahan, E. J. (1999). Evaluating the use of exploratory factor analysis in psychological research. *Psychological Methods*, 4, 272–299.

- Fehlinger, T., Stumpfenhorst, M., Stenzel, N., & Rief, W. (2013). Emotion regulation is the essential skill for improving depressive symptoms. *Journal of Affective Disorders*, 144, 116–122.
- Fengler, A. P., & Goodrich, N. (1979). Wives of Elderly Disabled Men: The Hidden Patients. *The Gerontologist*, 19, 175–183.
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P. R., Rimmer, E., & Scazufca, M. (2006). Global prevalence of dementia: a Delphi consensus study. *The Lancet*, 366, 9503, 2112–2117.
- Field, A. (2013). *Discovering statistics using IBM SPSS Statistics* (4th Edition). SAGE publications Ltd.
- Finch, J. (1995). Responsibilities, obligations and commitments. In I. Allen & E. Perkins (Eds.) *The future of family care for older people*. London: HMSO.
- Finucane, A. M., Dima, A., Ferreira, N., Halvorsen, M. (2012). Basic emotion profiles in healthy, chronic pain, depressed and PTSD individuals. *Clinical Psychology & Psychotherapy*, 19, 14–24.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219–239.
- Folkman, S., & Lazarus, R. S. (1984). Coping and adaptation. In W. D. Gentry (Ed.) *The handbook of behavioral medicine* (pp. 282–325). New York: Guilford.
- Folkman, S., & Lazarus, R. S. (1986). Stress processes and depressive symptomatology. *Journal of Abnormal Psychology*, 95, 107–113.
- Folkman, S., & Lazarus, R. S. (1988). Coping as a Mediator of Emotion. *Journal of Personality and Social Psychology*, 54, 466–475.

- Fox, J. R. E., & Froom, K. (2009). Eating Disorders: A Basic Emotion Perspective. *Clinical Psychology and Psychotherapy*, 16, 328–335.
- Fox, R. E., Smithson, E., Baillie, S., Nuno Ferreira, N., Mayr, I., & Power, M. J. (2012). Emotion Coupling and Regulation in Anorexia Nervosa. *Clinical Psychology and Psychotherapy*, 20, 319–333.
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-Based Psychological Treatments for Distress in Family Caregivers of Older Adults. *Psychology and Aging*, 22, 37–51.
- Gallichio, L., Siddiqi, N., Landenberg, P., Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, 17, 154–163.
- Gangstad, B., Norman, P., & Barton, P. J (2009). Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology*, 54, 69–75.
- Gaugler, J. E., Davey, A., Pearlin, L. I., & Zarit, S. H. (2000). Modeling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging*, 15, 437–450.
- Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003a). Predicting institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, 43, 219–229.
- Gaugler, J.E., Pot, A.M., & Zarit, S.H. (2007). Long-term adaptation to institutionalization in dementia caregivers. *The Gerontologist*, 47, 730–740.
- Gaugler, J.E., Roth, D.L., Hayley, W. E., & Mittelman, M. S. (2008). Can Counseling and Support Reduce Burden and Depressive Symptoms in Caregivers of People with Alzheimer's Disease During the Transition to Institutionalization? Results from the New York University Caregiver Intervention Study. *Journal of the American Geriatric Society*, 56, 421–428.

- Gaugler, J.E., Roth, D.L., Hayley, W. E., & Mittelman, M. S. (2011). Modelling trajectories and transitions: results from the New York University caregiver intervention. *Nursing Research*, 60, S28–S37.
- Gaugler, J. E., Yu, F., Krichbaum, K., Wyman, J. F. (2009a). Predictors of Nursing Home Admission for Persons with Dementia. *Medical Care*, 47, 191–198.
- Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2009b). Predictors of Change in Caregiver Burden and Depressive Symptoms Following Nursing Home Admission. *Psychology and Aging*, 24, 385–396.
- Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine*, 8:85.
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003b). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging*, 18, 171–180.
- George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26, 253–259.
- Gilhooley, M. L. M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology*, 57, 35–44.
- Gilley, D. W. Judith J. McCann, J. J., Julia L. Bienias, J. L., & Evans, D. A. (2005). Caregiver Psychological Adjustment and Institutionalization of Persons With Alzheimer's Disease. *Journal of Aging and Health*, 17, 172–189.
- Gonyea, J. G., Parisa, R., & de Saxe Zerdena, L. (2008). Adult daughters and aging mothers: The role of guilt in the experience of caregiver burden. *Aging & Mental Health*, 12, 559–567.
- Gonzalez, E. W., Polansky, M., Lippa, C. F., Walker, D., & Feng, D. (2011). Family Caregivers At Risk: Who Are They? *Issues in Mental Health Nursing*, 32, 528–536.

- Goy, E., Freeman, M., & Kansagara, D. (2010). A systematic evidence review of interventions for non-professional caregivers of individuals with dementia. Department of Veterans Affairs Health Services Research & Development Services. VA-ESP Project #05-225.
- Graham, S. M., Huang, J. Y., Clark, M. S., & Helgeson, V. S. (2008). The Positives of Negative Emotions: Willingness to Express Negative Emotions Promotes Relationships. *Personality and Social Psychology Bulletin*, 34, 394-406.
- Grant, I., Adler, K. A., Patterson, T. L., Dimsdale, J. E., Ziegler, M. G., & Irwin, M. R. (2002). Health consequences of Alzheimer's caregiving transitions: Effects of placement and bereavement. *Psychosomatic Medicine*, 64, 477-486.
- Grazt, K. L. & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of Psychopathology and Behavioral Assessment*, 26, 41-54.
- Gross, J. J. (1998). Antecedent and response-focused emotion regulation: Divergent consequences for experience, expression, and physiology. *Journal of Personality and Social Psychology*, 74, 224-237.
- Gross, J. J. (1999). Emotion Regulation: Past, Present, Future. *Cognition and Emotion*, 13, 551-573.
- Gross, J. J. & John, O. P. (2002). Wise emotion regulation. In L. F. Barrett & P. Salovey (Eds.) *The wisdom of feelings: Psychological processes in emotional intelligence* (pp. 297-318). New York: Guilford Press.
- Gross, J. J., & John, O.P. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. *Journal of Personality and Social Psychology*, 85, 348-362.
- Gross, J. J., & Munoz, R. F. (1995). Emotion Regulation and Mental Health. *Clinical Psychology: Science and Practice*, 2, 151-164.

- Gross, J. J., & Thomson, R. A. (2007). Emotion regulation: conceptual foundations. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 3–26). The Guildford Press. New York: London.
- Hamilton, M. (1960). A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry*, 23, 56–62.
- Harden, A., Rees, R., Shepherd, J., Brunton, G., Oliver, G., & Oakley, A. (2001). Young people and mental health: a systematic review of research on barriers and facilitators. EPPI Report, September 2001.
- Harre, R. (1986). An outline of the social constructionist viewpoint. In R. Harre (Ed.) *The social construction of emotions* (pp. 2–14). Oxford, England: Basil Blackwell.
- Hayley, W., Levine, E. G., Brown, S. L., Berry, J. W., & Hughes, G. H. (1987). Psychological, social and health consequences of caring for a relative with senile dementia. *Journal of the American Geriatrics Society*, 35, 405–411.
- Hayley, W., & Pardo, K. M. (1989). Relationship of severity of dementia to caregiving stressors. *Psychology and Aging*, 4, 389–392.
- Hazan, C., & Shaver, P. (1987). Romantic love conceptualized as an attachment process. *Journal of Personality and Social Psychology*, 52, 511–524.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the Death of a Loved One and Mental Health in Bereaved Caregivers of Patients with Dementia: Findings from the REACH Study. *Journal of Palliative Medicine*, 9, 683–693.
- Hennings, J., Froggatt, K., & Payne, S. (2013). Spouse caregivers of people with advanced dementia in nursing homes: A longitudinal narrative study. *Palliative Medicine*, 0, 1–9.
- Hérbert, R., Bravo, G., & Prévile, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, 19, 494–507.

- Hicks, J. A., Trent, J., Davis, W. E., King, L. A. (2012). Positive affect, meaning in life, and future time perspective: An application of socioemotional selectivity theory. *Psychology and Aging*, 27, 181–189.
- Ho, S. M. Y., Chan, C. L. W., & Ho, R. T. H. (2004). Posttraumatic growth in chinese cancer survivors. *Psycho-Oncology*, 13, 377–389.
- Hong & Kim, (2008). Family caregiver burden by relationship to care recipient with dementia in Korea. *Geriatric Nursing*, 29, 267–274.
- Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., Martin, R. L. (1982). A clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140, 566–578.
- Jansson, W., Nordberg, G., Grafström, M. (2001). Patterns of elderly spousal caregiving in dementia care: an observational study, *Journal of Advanced Nursing*, 34, 804–812.
- Jobe, J. B., Tourangeau, R., & Smith, A. F. (1993). Contributions of survey research to the understanding of memory. *Applied Cognitive Psychology*, 7, 567–584.
- John, O. P., & Gross, J. J. (2007). Individual differences in emotion regulation. In J. J. Gross (Ed.) *Handbook of emotion regulation* (pp. 351–372). The Guildford Press. New York: London.
- Joling, K.J., Hout, H.P.J. van, Schellevis, F.G., Horst, H. E. van der, Scheltens, P., Marwijk, H.W.J. van (2010). Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *American Journal of Geriatric Psychiatry*, 18, 146–153.
- Joseph, S., & Linley, P.A. (2006). Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review*, 26, 1041–1053.
- Joseph, S., Murphy, D., Regel, S. (2012). Special Issue Article An affective–cognitive processing model of post-traumatic growth. *Clinical Psychology and Psychotherapy*, 19, 316–325.

- Kahn, R. L., Goldfarb, A. I., Pollack, M., Peck, R. (1960). Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry*, 117, 326–328.
- Kaiser & Panegyres, (2006). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimers Disease and Other Dementias*, 21, 398–402.
- Kiecolt-glaser, J. K. Dura, J. R, Speicher, C. E., Trask, J., & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine*, 53, 345–362.
- Kinny, J. M., & Stephens, M. A. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology of Aging*, 4, 402–408.
- Kim, Y., Carver, C., Deci, E., Kasser, T. (2008). Adult attachment and psychological wellbeing in cancer caregivers: the meditational role of spouses' motives for care giving. *Health Psychology*, 27, S144–S154.
- Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483–503.
- Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. HTA Initiative 13, Alberta Heritage Foundation for Medical Research.
- Knapp, M., & Prince, M. (2007). Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London School of Economics). Alzheimer's Society: London.
- Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33, 240–248.
- Knop, D. S., Bergman-Evans, B., & McCabe, B. W. (1998). In sickness and in health: An exploration of the perceived quality of the marital relationship, coping and depression in caregivers of spouses with Alzheimer's disease. *Journal of Psychosocial Nursing and Mental Health Services*, 36, 16-21.

- Kramer, B. J. (2000). Husbands caring for wives with dementia: A longitudinal study of continuity and change. *Health and Social Work, 25*, 97–107.
- Laidlaw, K., & Thompson, L. W. (2008). Cognitive behaviour therapy with depressed older people. In K. Laidlaw & B. Knight (Eds.) *Handbook of emotional disorders in later life: assessment and treatment*. Oxford University Press.
- Larson, E. B., Shadlen, M. F., Wang, L., McCormick, W. C., Bowen, J. D., Teri, L. & Kukull, W. A. (2004). Survival after initial diagnosis of Alzheimer disease. *Annals of Internal Medicine, 140*, 501–509.
- Lazarus, R. S. (1991). Cognition and motivation in emotion. *American Psychologist, 46*, 352–367.
- Lazarus, R.S., & Folkman, S. (1974). *Stress, Appraisal and Coping*. New York: Springer.
- Lewis, M. L., Hepburn, K., Narayan, S., & Kirk, L. N. (2005). Relationship matters in dementia caregiving. *American Journal of Alzheimer's Disease and Other Dementias, 20*, 341–347.
- Li, R., Cooper, C., Bradley, J., Amanda Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analysis, *Journal of Affective Disorders, 139*, 1–11.
- Lindgren, C. L., Connelly, C. T., Gaspar, H. L. (1999). Grief in Spouse and Children Caregivers of Dementia Patients. *Western Journal of Nursing Research, 21*, 521–537.
- Linley, P. A., & Joseph, S. (2004). Positive Change Following Trauma and Adversity: A Review. *Journal of Traumatic Stress, 17*, 11–21.
- Linley, P. A., Andrews, L., & Joseph, S. (2007). Confirmatory Factor Analysis of the Posttraumatic Growth Inventory. *Journal of Loss and Trauma: International Perspectives on Stress & Coping, 12*, 321 – 332.
- Livingstone, K., Harper, S., Gillanders, D. (2009). An exploration of emotion regulation in psychosis. *Clinical Psychology & Psychotherapy, 16*, 418–430.

- Livingston, G., Leavey, G., Manela, M., Livingston, D., Rait, G., Sampson, E., Bavishi, S., Shahriyarmolki, K., & Cooper, C. (2010). Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *British Medical Journal*, 341,c4184, August 18.
- Lopes, P. N., Salovey, P., Cote, S., & Beers, M. (2005). Emotion regulation abilities and the quality of social interaction. *Emotion*, 5, 113–118.
- Luengo-Fernandez, R., Leal, J., & Gray, A. (2010). *The economic burden of dementia and associated research funding in the United Kingdom*. A report produced by the Health Economics Research Centre, University of Oxford for the Alzheimer's Research Trust.
- Lundh, U., Sandberg, J., Nolan, M. (2000). 'I don't have any other choice': spouses' experiences of placing a partner in a care home for older people in Sweden. *Journal of Advanced Nursing*, 32, 1178–1186.
- Luppino, F. S., de Wit, L. M., Bouvy, P. F., Stijnen, T., Cuijpers, P., Penninx, B. W. J. H., & Zitman, F. G. (2010). Overweight, Obesity, and Depression: A Systematic Review and Meta-analysis of Longitudinal Studies. *Archives of General Psychiatry*, 67, 220–229.
- Lutzsky, S. M., & Knight, B. G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9, 513–519.
- Lyness, J. M., Noel, K., Cox, T., King, C., Conwell, D. A., Caine, Y. (1997). Screening for depression in elderly primary care patients. *Archives of Internal Medicine*, 157, 449–454.
- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological methods*, 4, 84–99.
- Magai, C., Consedine, N. S., Krivoshekova, Y. S., Kudadjie-Gyamfi, E., McPherson, R. (2006). Emotion experience and expression across the adult life span: Insights from a multimodal assessment study. *Psychology and Aging*, 21, 303–317.
- Malfullul, Y. M., & Morriss, R. K. (2000). Determinants of satisfaction with care and emotional distress among informal carers of demented and non-demented elderly patients. *International Journal of Geriatric Psychiatry*, 15, 594–599.

- Marroquin, B. (2011). Interpersonal emotion regulation as a mechanism of social support in depression. *Clinical Psychology Review*, 31, 1276–1290.
- Martin, M., Peter-Wight, M., Braun, M., Hornung, R., & Scholz, U. (2009). The 3-phase-model of dyadic adaptation to dementia: why it might sometimes be better to be worse. *European Journal of Ageing*, 6, 291–301.
- Marwit, S. J., & Meuser, T. M. (2002). Development and initial validation of an inventory to measure grief in caregivers of persons with Alzheimer's disease. *The Gerontologist*, 42, 751–765.
- Matsuda, O., Hasebe, N., Ikhara, K., Futatsuya, K., Akahane, N. (1997). Longitudinal study of the mental health of caregivers caring for elderly patients with dementia: Effect of institutional placement on mental health. *Psychiatry and Clinical Neuroscience*, 51, 289–293.
- Mausbach, B. T., Aschbacher, K., Patterson, T. L., von Kanel, R., Dimsdale, J. E., Mills, P. J., (2007). Effects of placement and bereavement on psychological well-being and cardiovascular risk in alzheimer's caregivers: A longitudinal analysis. *Journal of Psychosomatic Research*, 62, 439–445.
- Mauss, I. B., Bunge, S. A., & Gross, J. J. (2007). Automatic Emotion Regulation. *Social and Personality Psychology Compass*, 1, 146–167.
- McCausland, J., & Pakenham, K. I. (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 15, 853–869.
- McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, 7, 81–91.
- McGovern, (2011). Couple meaning-making and dementia: challenges to the deficit model. *Journal of Gerontological Social Work*, 54, 678–690.

- McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15, 522–530.
- Metts, S., Sprecher, & Cupach (1991). Retrospective self-reports. In B. M. Montgomery & A. Duck (Eds). *Studying Interpersonal Interaction* (pp. 162–175). The Guildford Press.
- Meuser, T.M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41, 658–670.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498–507.
- Mills, P. J., Ancoli-Israel, S., & Grant, I. (2009). Effects of Gender and Dementia Severity on Alzheimer's Disease Caregivers' Sleep and Biomarkers of Coagulation and Inflammation. *Brain, Behavior and Immunity*, 23, 605–610.
- Mioshi, E., Kipps, C. M., & Hodges, J. R. (2009). Activities of daily living in behavioral variant Frontotemporal Dementia: differences in caregiver and performance-based assessments. *Alzheimer Disease and Associated Disorders*, 23, 70–76.
- Mittelman, M.S., & Epstein, C. (2009). The NYU caregiver intervention, the original study and issues in early translations in diverse community settings, *The Gerontologist*, 49, 387–387.
- Mittelman, M., Haley, W. E., Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*, 67, 1592–1599.
- Montgomery, R. J. V., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs adult children. *Journal of Gerontology*, 49, S62–S74.
- Moore, J. T., Bobula, J. A., Short, T. B., Mischel, M. (1983). A functional dementia scale. *Journal of Family Practice*, 16, 499–503.
- Morrill, E., F., Brewer, N. T., O'Neill, Lillie, S. E., Dees, E. C., Carey, L. A. Rimer, B. K.

- (2008). The interaction of post-traumatic growth and post-traumatic stress symptoms in predicting depressive symptoms and quality of life. *Psycho-Oncology*, 17, 948–953.
- Morris, R. G., Morris, L. W., & Britton, P. G. (1988). Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British Journal of Psychiatry*, 153, 147–156.
- Morris, L.W., Morris, R.G., & Britton, P.G, (1989). Cognitive style and perceived control in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology*, 62, 173–179.
- Morycz, R. K. (1985). Caregiving strain and desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging*, 7, 329–361.
- Motenko, A. K. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *The Gerontologist*, 29, 166–172.
- Mui, A. C., Burnette, D., & Mei Chen, L. (2002). Cross cultural assessment of geriatric depression: a review of CES-D and GDS. In J. H. Skinner, J.A. Teresi, D. Holmes, S. M. Stahl, A. L. Stewart,. (Eds.) *Multicultural measurement in older populations* (pp.147–178). Springer publishing company.
- Mullin, J., Simpson, J., & Froggatt, K. (2011). Experiences of spouses of people with dementia in long-term care. *Dementia*, 12, 177–191.
- Mulrow, C. D., Williams, J. W., Gerety, M. B., Ramirez, G. Montiel, O.M., Kerber, C. (1995). Case-finding instruments for depression in primary care settings. *Annals of Internal Medicine*, 122, 913–921.
- Nerken, I. R. (1993). Grief and the reflective self: toward a clearer model of loss resolution and growth. *Death Studies*, 17, 1–26.
- Nolan & Dellasega, (2000). 'I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, 31, 759–767.

- Nolen-Hoeksema, S., & Aldao, A. (2011). Gender and age differences in emotion regulation strategies and their relationship to depressive symptoms. *Personality and Individual Differences*, 51, 704–708.
- Nuffield Council on Bioethics. *Dementia: Ethical Issues* (2009). Cambridge Publishers Ltd.
- Nunnemann S., Last, D., Schuster, T., Förstl, H., Kurz, A., & Diehl-Schmid, J. (2011) Survival in a German population with frontotemporal lobar degeneration. *Neuroepidemiology*, 37, 160–165.
- Ochsner, K. N., & Gross, J. J. (2004). Thinking makes it so: a social cognitive neuroscience approach to emotion regulation. In R. F. Baumeister & K. D. Vohs (Eds.) *Handbook of self-regulation: Research, theory and applications* (pp. 229–255). New York: Guildford Press.
- Orgeta, V. (2009). Specificity of age differences in emotion regulation. *Aging & Mental Health*, 13, 818–826.
- Ornstein, K., & Gaugler, J. E. (2012). The problem with “problem behaviors”: a systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. *International Psychogeriatrics*, 24, 1536–1552.
- Ory, M., Hoffman, H., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *Gerontologist*, 39, 177–186.
- Ory, M., Yee, J., Tennstedt, S., & Schulz, R. (2000). The extent and impact of dementia care: Unique challenges experienced by family caregivers. In Schulz, R. (Ed.), *Handbook on Dementia Caregiving: Evidence-based interventions for family caregivers*. New York: Springer.
- O’Shaughnessy, M., Lee, K., Lintern, T. (2010). Changes in the couple relationship in dementia care: spouse carers’ experiences. *Dementia*, 9, 237–258.

- Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's Disease and related dementias. *The Gerontologist*, 47, 798–809.
- Oyebode, J. (2003). Assessment of carers' psychological needs. *Advances in Psychiatric Treatment*, 9, 45–53.
- Pagel, M. D., Becker, J., & Coppel, D. (1985). Loss of control, self-blame, and depression: An investigation of spouse caregivers of Alzheimer's disease patients. *Journal of Abnormal Psychology*, 94, 169–182.
- Pakenham, K. I. (2005). The positive impact of multiple sclerosis (MS) on carers: Associations between carer benefit finding and positive and negative outcomes. *Disability and Rehabilitation*, 27, 985–997.
- Parker, D., Mills, S., & Abbey, J. (2008). Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence Based Healthcare*, 6, 137–172.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594.
- Pearlin, L. I. (1994). Conceptual strategies for the study of caregiver stress. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.) *Stress effects on family caregivers of Alzheimer's patients: Research and interventions* (pp. 3–21). New York: Springer.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behaviour*, 19, 2–21.
- Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health*, 10, 539–548.
- Perry, J., & O'Connor, D. (2002). Preserving personhood: (Re)Membering the spouse with dementia. *Family Relations*, 51, 55–61.

- Phillips, K. F. V., & Power, M. J. (2007). A new self-report measure of emotion regulation in adolescents: The Regulation of Emotions Questionnaire. *Clinical Psychology and Psychotherapy*, 145–156.
- Pinquart, M., & Sörensen, S. (2003a). Associations of stressors and uplifts of care with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology*, 58, 112 – 128.
- Pinquart, M., & Sörensen, S. (2003b). Predictors of caregiver burden and depressive mood: A meta-analysis. *Journal of Gerontology, Psychological Sciences*, 58, 112–128.
- Pinquart, M., Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging and Mental Health*, 8, 438–449.
- Pinquart, M., & Sörensen, S. (2006a). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journal of Gerontology, Psychological Sciences*, 61, 33–45.
- Pinquart, M., & Sörensen, S. (2006b). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18, 577–595.
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journal of Gerontology: Psychological and Social Sciences*, 62, 126–137.
- Pinquart, M., & Sörensen, S. (2011). Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults: A Meta-Analytic Comparison. *Psychology and Aging*, 26, 1–14.
- Plutchik, R. (1980). *Emotion: A psychoevolutionary synthesis*. New York: Harper & Row.
- Power, M.J. (2006). The structure of emotion: An empirical comparison of six models. *Cognition and Emotion*, 20, 694–713.
- Power, M. J., & Tarsia, M. (2007). Basic and complex emotions in depression and anxiety. *Clinical Psychology and Psychotherapy*, 14, 19–31.

- Prati, G., & Pietrantonio, L. (2009). Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: A meta-analysis. *Journal of Loss and Trauma*, 14, 364–388.
- Pruchno, R. A., Michaels, J. E., & Potashnik, S. L. (1990). Predictors of institutionalization among Alzheimer disease victims with caregiving spouses. *Journal of Gerontology: Social Sciences*, 45, 259–266.
- Pruchno, R. A., & Resch, N. L. (1989). Aberrant behaviors and Alzheimer's Disease: Mental health effects on spouse caregivers. *Journal of Gerontology: Social Sciences*, 44, 177–182.
- Qualls, S. H. (2008). Caregiver family therapy. In B. Knight & K. Laidlaw (Eds.) *Handbook of emotional disorders in older adults* (pp. 183–209). Oxford University Press.
- Quayhagen, M. P., & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiving role. *The Gerontologist*, 28, 391–396.
- Quinn, C., Clare, L., & Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health*, 13, 143–154.
- Radloff, L. (1977). The CES-D scale: a self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–401.
- Reisberg, B., Ferris, S. H., de Leon, M. J., Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139, 361–369.
- Riordan J. M., Bennett A. V. (1998). An evaluation of an augmented domiciliary service to older people with dementia and their carers. *Aging and Mental Health*, 2, 137–143.
- Roach, L., Laidlaw, K., Gillanders, D., Quinn, K. (2013). Validation of the Caregiver Guilt Questionnaire (CGQ) in a sample of British dementia caregivers. (in submission). *International Psychogeriatrics*.

- Robinson, K. M., Adkisson, P., & Weinrich, S. (2001). Problem behaviour, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease. *Journal of Advanced Nursing*, 36, 573–582.
- Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C., & Volicer, L. (2005). End-of-life care and dementia. *Reviews in Clinical Gerontology*, 15, 135–148.
- Rodriguez, G., De Leo, C., Girtler, N., Vitali, P., Grossi, E., Nobili, F., (2003). Psychological and social aspects in management of Alzheimer's patients: an inquiry among caregivers. *Neurological Science*, 24, 329–335.
- Rudd, M. G., Viney, L. L., & Preston, C. A (1999). The Grief Experienced by Spousal Caregivers of Dementia Patients: the Role of Place of Care of Patient and Gender of Caregiver. *The International Journal of Aging and Human Development*, 48, 217–240.
- Ryan, A. and Scullion, H. (2000). Nursing home placement: an exploration of the experience of family carers. *Journal of Advanced Nursing*, 32, 1187–1195.
- Sachs, G. A., Shega, J. W., Cox-Hayley, D. (2004). Barriers to Excellent End-of-life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19, 1057–1063.
- Sanders, S., Ott, C. H., Kelber, S. (2008). The Experience of high levels of grief in caregivers of persons with Alzheimer's disease. *Death Studies*, 31, 495–523.
- Scarff, S., & Zultner, A. (2012). *Dementia: the journey ahead - a practical guide for in-home caregivers*. Langdon Street Press.
- Scheibe, S., & Cartensen, L. L. (2010). Emotional Aging: Recent Findings and Future Trends. *Journal of Gerontology: Psychological Sciences*, 65, 135–144.
- Scheibe, S., & Blanchard-Fields, F. (2009). Effects of regulating emotions on cognitive performance: What is costly for young adults is not so costly for older adults. *Psychology and Aging*, 24, 217–223.
- Scottish Government (2010). Scotland's National Dementia Strategy. Edinburgh.

- Scottish Government (2013). Scotland's National Dementia Strategy: 2013-16. Edinburgh.
- Scottish Government (2011a). Standards of care for dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy. Edinburgh.
- Scottish Government (2011b). National guidance that evidences the use of psychological therapies. Edinburgh.
- Schore, A. N. (2003). *Affect regulation and the repair of the self*. New York: W. W. Norton & Company, Inc.
- Schultz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: the caregiver health effects. *Journal of the American Medical Association*, 282, 2215–2219.
- Schulz, R., Beach, S.R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., Jackson, S., Burton, L. (2001). Involvement in caregiving and adjustment to death of a spouse: findings from the Caregiver Health Effects Study. *Journal of the American Medical Association*, 285, 3123–3129.
- Schulz, R, Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., & Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, 292, 961–967.
- Schulz R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., Jackson, S. (1997). Health effects of caregiving: the Caregiver Health Effects Study: an ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, 19, 110–116.
- Schultz, R., O'Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The Gerontologist*, 35,771–791.
- Schulz, R., & Williamson, G. M. (1994). Health effects of caregiving: Prevalence of mental and physical illness in Alzheimer's caregivers. In E. Light, G. Niederehe, & B. D. Lebowitz (Eds.) *Stress effects on family caregivers of Alzheimer's patients: Research and interventions* (pp. 38–63). New York: Springer.

- Searson, R., Hendry, A.M., Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging & Mental Health*, 12, 276–282.
- Şenol-Durak, E., & Ayvaşık, H. B. (2010). Factors associated with posttraumatic growth among the spouses of myocardial infarction patients. *Journal of Health Psychology*, 15, 5–95.
- Schaefer, J. A., & Moos, R. H. (1992). Life crisis and personal growth. In B. N. Carpenter (Ed.), *Personal coping: Theory, research, and application* (pp. 149–170). Westport, CT, Praeger Publishers/Greenwood Publishing Group.
- Sharp, L. K., & Lipsky, M. S. (2002). Screening for depression across the lifespan: a review of measures for use in primary care settings. *American Family Physician*, 15, 1001–1008.
- Shaw, W. S., Semple, S. J., Ho, S., Irwin, M. R., Hauger, R. L., Grant, I., et al. Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine*, 19, 101–109.
- Sheikh, A. I., & Marotta, S. A. (2005). A cross-validation study of the posttraumatic growth inventory. *Measurement and Evaluation in Counseling and Development*, 38, 66–77.
- Shim, B., Barroso, J., Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International Journal of Nursing Studies*, 49, 220–229.
- Scottish Intercollegiate Guidelines Network (SIGN) 50: A guideline developer's handbook. November 2011.
- Snyder, B., & Keefe, K. (1985). The unmet needs of family caregivers for frail and disabled adults. *Social Work Health Care*, 10, 1–14.
- Spaid, W.M., & Barusch, A.S. (1994). Emotional closeness and caregiver burden in marital relationship. *Journal of Gerontological Social Work*, 21, 197–211.

- Spanier, G. B., & Thompson, L. A. (1982). A confirmatory analysis of the dyadic adjustment scale. *Journal of Marriage and Families*, 38, 731–741.
- Stevens, J. P. (2009). *Applied multivariate statistics for the social sciences*. (5th Edition) New York: Routledge.
- Szasz, P. L., Szentagotai, A. & Hofmann, S. G. (2011). The effect of emotion regulation strategies on anger. *Behaviour Research and Therapy*, 49, 114–119.
- Tabachnick, B. G., & Fidell, L. S. (2007). *A Practical Approach to using Multivariate Analyses Using Multivariate Statistics* (6th edition). Boston: Pearson Education.
- Taku, K., Cann, A. C., Calhoun, L. G., & Tedeschi, R. G. (2008). The factor structure of the posttraumatic growth inventory: A comparison of five models using confirmatory factor analysis. *Journal of Traumatic Stress*, 21, 158–164.
- Tamres, L. K., Janicki, D., & Helgeson, V. S. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review*, 6, 2–30.
- Taylor, D. H., Ezell, M., Kuchibhatla, M., Ostbye, T., & Clipp, E. C. (2008). Identifying trajectories of depressive symptoms for women caring for their husbands with dementia. *Journal of the American Geriatrics Society*, 56, 322–327.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The posttraumatic growth inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455–471.
- Tedeschi, R. G., & Calhoun, L. G. (2004). Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological Inquiry* 15, 1–18.
- Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (Eds.). (1998). *Posttraumatic growth: Positive changes in the aftermath of crisis*. Mahwah, NJ: Erlbaum.

- Teri, L., Logsdon, R. G., & Uomoto J., & McCurry, S. M. (1997). Behavioral treatment of depression in dementia patients: a controlled clinical trial. *Journal of Gerontology Series B Psychological Sciences*, 52, 159–166.
- Thoits, P. A. (2010). Stress and health: major findings and policy implications. *Journal of Health and Social Behavior*, 51, S41–S53.
- Tickle, M., Milsom, K. M., Blinkhorn, A. S., & Worthington, H. V. (2003). Comparing different methods to detect and correct nonresponse bias in postal questionnaire studies. *Journal of Public Health Dentistry*, 63, 112–118.
- Tilse, C. (1998). Continuing or refusing to care: The meaning of placing a spouse in long term care. *American Journal of Alzheimer's Disease*, 13, 29–33.
- Townsend, A. L. (1990). Nursing home care and family caregivers' stress. In M. A. P. Stephens, J. H. Crowther, S. E. Hobfoll, & D. L. Tennenbaum (Eds.). *Stress and coping in later-life families*. Washington, DC: Hemisphere.
- Train, G., Nurock, S., Kitchen, G., Manela, M., & Livingston, G. (2005). A qualitative study of the views of residents with dementia, their relatives and staff about work practice in long-term care settings. *International Psychogeriatrics*, 17, 237–251.
- Tugade, M. M., Fredrickson, B. L. (2004). Resilient Individuals Use Positive Emotions to Bounce Back From Negative Emotional Experiences. *Journal of Personality and Social Psychology*, 86, 320–333.
- Tweedy, M. P., & Guarnaccia, C. A. (2007). Change in depression of spousal caregivers of dementia patients following patient's death. *Omega: Journal of Death and Dying*, 56, 217–228.
- Van der Kooy, K., Van Hout, H., Marwijk, H., Marten, H., Stehouwer, C., & Beekman, A. (2007). Depression and the risk for cardiovascular diseases: systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*, 22, 613–626.

- Vishnevsky, T., Cann, A., Calhoun, L. G., Tedeschi, R. G., & Demakis, G. J. (2010). Gender differences in self-reported posttraumatic growth: a meta-analysis. *Psychology of Women quarterly*, 34, 110–120.
- Vitaliano, P. P., Echeverria, D., Yi, J., Phillips, P. E., Young, H., & Siegler, I. C. (2005). Psychophysiological mediators of caregiver stress and differential cognitive decline. *Psychology & Aging*, 20, 402–411.
- Vitaliano, P. P., Young, H. M., & Russo, J. (1991). Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist*, 31, 67–75.
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, 129, 946–972.
- Von Kanel, R., Mausbach, B. T., Dimsdale, J. E., Mills, P. J., Patterson, T. L., Ancoli-israel, S., Ziegler, M. G., Roepke, S. K., Chattillion, E. A., Allison, M., & Grant, I. (2012). Effect of chronic dementia caregiving and major transitions in the caregiving situation on kidney function: a longitudinal study. *Psychosomatic Medicine*, 74, 214–220.
- Waite, A., Bebbington, P., Skelton-Robinson, M., Orrell, M. (2004). Social factors and depression in carers of people with dementia. *International Journal of Geriatric Psychiatry*, 19, 582–587.
- Walsh, J.S., Welch, H. G., Larson, E.B. (1990). Survival of outpatients with Alzheimer-type dementia. *Annals of International Medicine*, 113, 429–434.
- Weiss, T. (2002). Posttraumatic growth in women with breast cancer and their husbands: an inter-subjective validation study. *Journal of Psychosocial Oncology*, 65–80.
- Weiss, T. (2004). Correlates of posttraumatic growth in married breast cancer survivors. *Journal of Social and Clinical Psychology*, 23, 733–746.
- Widows, M. R., Jacobsen, P. B., Booth-Jones, M., & Fields, K. K. (2005). Predictors of posttraumatic growth following bone marrow transplantation for cancer. *Health Psychology*, 24, 266–273.

- Wild, N. D., & Paivio, S. C., (2002). Psychological adjustment, coping, and emotion regulation as predictors of posttraumatic growth. *Journal of Aggression, Maltreatment & Trauma*, 97–122.
- Williamson, G. M., & Schulz, R. (1990). Relationship orientation, quality of prior relationship, and distress among caregivers of Alzheimer's patients. *Psychology and Aging*, 5, 502–509.
- Winblad, B., Wimo, A., Almkvist, O. (2000). Outcome measures in Alzheimer's disease: do they go far enough? *Dementia and Geriatric Cognitive Disorders*. 11, 3–10.
- Wisniewski S., Belle, S. H., Coon, D., Marcus, S., Ory, M., Burgio, L., & Schultz, R. (2003) The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project design and baseline characteristics. *Psychology and Aging*, 18, 375–384.
- Wolfson, C., Wolfson, D.B., Asgharian, M., Emile, C., Ostbye, R., Rockwood, K., Hogan, D. B. (2001). A re-evaluation of the duration of survival after the onset of dementia. *The New England Journal of Medicine*, 344,1111–1116.
- Wright, L. K. (1994a). Alzheimer's Disease spousal caregivers: longitudinal changes in health, depression, and coping. *Journal of Gerontological Nursing*, 20, 33–48.
- Wright, L. K. (1994b). Alzheimer's disease afflicted spouses who remain at home: Can human dialectics explain the findings? *Social Science & Medicine*, 38, 1037–1046.
- Wright, F. (1998). *Continuing to care: the effect on spouses and children of an older person's admission to a care home*. Joseph Rowntree Foundation.
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40, 147–164.
- Yesavage, J. A., Brink,T. L., Rose, T. L., Lum, O., & Huang, V. S. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37–39.

- Zarit, S., & Femia, E. (2008). A future for family care and dementia intervention research? Challenges and strategies. *Aging & Mental Health*, 12, 5–13.
- Zarit, S. H., & Gaugler, J. E. (2006). Care by families for late stage dementia. In A. Burns, & B. Winblad (Eds.) *Severe Dementia*. New York, NY: John Wiley & Sons Ltd.
- Zarit, S.H., Reever, K., & Bach-Peterson, J. (1980). Relatives of impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 373–377.
- Zarit, S. H., Todd, P. A., Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26, 260–266.
- Zarit, S. H., & Whitlatch, C.J. (1992). Institutional placement: Phases of transition. *The Gerontologist*, 32,665–672.
- Zoeller, T., & Maercker, A. (2006). Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review*, 26, 626–653.
- Zung, W. W. K. (1965). A self-rating depression scale. *Archives of General Psychiatry*, 12, 63–70.
- Zwalen, D., Hagenbuch, N., Carley, M. I., Jenewein, J., Buchi, S. (2010). Posttraumatic growth in cancer patients and partners-effects of role, gender and the dyad on couples' posttraumatic growth experience. *Psycho-Oncology*, 19, 12–20.

APPENDIX 1 Author guidelines for journal articles written for submission to: International Psychogeriatrics

CAMBRIDGE | Instructions for Contributors

International Psychogeriatrics

Please read these instructions carefully before submitting articles. Articles which are not prepared in accordance with these guidelines will be returned to authors unreviewed.

Scope and contributions

International Psychogeriatrics is written by and for those doing clinical, teaching, and research work with elderly people. It is the official journal of the International Psychogeriatric Association (IPA) and is published by Cambridge University Press, Cambridge, UK. Although it is concerned primarily with psychogeriatrics, the journal welcomes contributions from all concerned with the field of mental health and aging. Original research papers are particularly sought.

Contributions include original research articles, reviews of the literature, "for debate" articles, case reports, letters to the editor, book reviews and editorials. Apart from editorials, "for debate" articles and book reviews, which are commissioned, contributions to *International Psychogeriatrics* are spontaneously written and submitted by authors. Papers are reviewed by at least two expert reviewers selected by the Editor-in Chief. At present about half of the papers submitted are accepted for publication in this journal which is published twelve times per annum. The journal's Science Citation Index Impact Factor (2011) is 2.24. Submission of a paper implies that it is neither under consideration for publication elsewhere, nor previously published in English. Manuscripts must be formatted double-spaced with ample margins on all sides and the pages should be numbered. Please leave a spare line between paragraphs to enable typesetters to identify paragraph breaks without ambiguity. *International Psychogeriatrics* uses the spelling of American English. Manuscripts written by those whose primary language is not English should be edited carefully for language prior to submission. *International Psychogeriatrics* has a Language Advisory Panel of English speakers willing to check manuscripts for style prior to submission. Details can be found at both the journal website (<http://journals.cambridge.org/ipg>) under the related links icon and the IPA website (<http://www.ipa-online.org/>).

Submission of manuscripts

Manuscripts should be submitted online via our manuscript submission and tracking site, <http://mc.manuscriptcentral.com/ipg>. Full instructions for electronic submission are available directly from this site. If you are unsure of the suitability of your manuscript, please e-mail the abstract to the Journal Office before submitting online: ipaj-ed@unimelb.edu.au

To facilitate rapid reviewing, communications for peer review will be electronic and authors will need to supply a current e-mail address when registering to use the system.

When submitting your manuscript you will need to supply:

A cover letter, the manuscript with the text file in MS Word format, and all figures in TIFF or JPEG format. If the paper reports the results of a randomized controlled trial please ensure that it conforms to our requirements listed below under the heading 'Submission of randomized clinical trials' on page 2. If the research was paid for by a funding organization, the cover letter must contain the following three statements (this information does not have to be included in the manuscript itself but only in the cover letter). If the research was not paid for by a funding organization only the third statement is required:

1. That the authors have not entered into an agreement with the funding organization that has limited their ability to complete the research as planned and publish the results.
2. That the authors have had full control of all the primary data.

3. That the authors are willing to allow the journal to review their data if requested.

Submission of a manuscript will be taken to imply that all listed authors have seen the final version and approved it.

All papers will be assessed by two reviewers. If their opinions are too disparate to permit the Editor-in-Chief to make a decision on publication or the reviewers are unable to make clear recommendations, the paper will be assessed by a third reviewer. **The Editor-in-Chief's decision to accept, reject or request revision of the paper for publication will be final.** The abstract and author details will be seen by prospective reviewers of the manuscript. Authors can suggest the names and contact information of experts qualified to review the work, but the Editor-in-Chief is not obliged to follow these suggestions. Papers must bear the authors' names, titles (e.g., Dr, Professor, etc.), affiliation(s), and address(es). This information will be seen by reviewers. Reviewers' names will not be supplied to authors unless a reviewer asks to be so identified. Authors will be provided with a copyright transfer form to sign after acceptance of the manuscript, consenting to publication of the paper in *International Psychogeriatrics*.

The receipt of all submitted papers will be acknowledged. Authors who do not receive an acknowledgement of receipt of their paper within three weeks of submission should assume that their paper has not been received and should contact ipaj-ed@unimelb.edu.au, Professor Nicola Lautenschlager, Normanby House, St George's Hospital, 283 Cotham Road, Kew, Victoria, 3101, Australia, Tel: +61 3 9816 0485, Fax: + 61 3 9816 0477. Most authors can expect to receive an initial decision on the fate of their paper together with referees' reports within no more than 100 days of submission. Authors who have received no further communication 120 days after acknowledgment of receipt of their article should contact ipaj-ed@unimelb.edu.au.

Submission of papers reporting randomized controlled trials

In order to ensure the public availability of the results of randomized controlled trials, the International Committee of Medical Journal Editors has suggested that all such trials should be registered. In common with many leading medical journals *International Psychogeriatrics* has decided to follow this policy. Since 31 December 2006 we will not review any paper submitted to us reporting a randomized clinical trial unless the trial was registered in a public trial registry from the date it commenced recruitment or, if recruitment started before 30 November 2006, we require that the trial was registered no later than 30 November 2006. For further details on the reasons for this policy see the June 2006 editorial, Ames, D. (2006). Registration of Clinical Trials submitted for publication in *International Psychogeriatrics*. *International Psychogeriatrics*, 18, 191-193.

All manuscripts reporting randomized controlled trials should have the following sent with them or they will be returned to the authors.

- a. A check list and flow chart in accordance with the CONSORT guidelines which can be found at <http://www.consort-statement.org>. Please send in the checklist as a supplementary file and include the flow chart as Figure 1 in the manuscript.
- b. The trial protocol is to be submitted as a supplementary file. This will not be published but it is needed to appraise and peer review the paper.
- c. The registration number of the trial and the name of the trial registry in which it was registered. Please add these to the last line of the paper's structured abstract. Trials that began enrolment of patients after 31 December 2006 must have been registered in a public trials registry at or before the onset of enrolment to be considered for publication in *International Psychogeriatrics*. Trials that began enrolment prior to 30 November 2006 must have been registered no later than that date. Our criteria for a suitable public trial registry are: free to access; searchable; identification of trials by unique number; free or minimal cost for registration; validation of registered information; inclusion of details to identify the trial and the investigator within the registered entry (including the status of the trial); research question; methodology; intervention; and funding and sponsorship disclosed.

Organization and style of research articles

Title page and corresponding author: Each article must have a title page with the title of the article, a list of all authors and their titles, affiliations and addresses. Author qualifications should not be listed as these are not published in the journal. The title page should explicitly identify the author to whom correspondence about the study should be addressed and that author's email address, telephone number, fax number and postal address must be clearly stated.

Abstract: Abstracts should be brief, structured and should incorporate the 4 sub-headings: background, method(s), results and conclusion(s). Abstracts should communicate the primary findings and significance of the research. They should not exceed 250 words in length.

Key words: Under this heading and beneath the abstract, please list up to 8 words for the purpose of indexing.

Running title: This should contain no more than 50 characters including spaces.

Introduction: Briefly state the relevant background to the study to provide the necessary information and context to enable non-specialists to appreciate the objectives and significance of the paper. Most introductions to articles received for review are too long.

Methods: Materials and procedures should be described in sufficient detail to enable replication. Any statistical procedures used should be outlined and their use should be justified here. Results should not be included in the Method(s) section. If statistical procedures are used, they should be described here in adequate detail. Choice of statistical technique should be justified including some indication of the appropriateness of the data for the technique chosen. Adequacy of the sample size for the statistical technique(s) used must be addressed. If appropriate, a description of the statistical power of the study should be provided. If multiple univariate significant tests are used, probability values (p-values) should be adjusted for multiple comparisons, or alternatively a multivariate test should be considered.

Further advice about statistics and *International Psychogeriatrics* can be found in the following article: Chibnall, J. (2000) Some basic issues for clinicians concerning things statistical. *International Psychogeriatrics*, 12, 3-7. The following article may also be of assistance to intending contributors: Chibnall J.T. (2004). Statistical audit of original research articles in *International Psychogeriatrics* for the year 2003. *International Psychogeriatrics* 16, 389-396. Both of these are available at the *International Psychogeriatrics* website by following the link to [Statistical Advice for intending contributors](http://journals.cambridge.org/ipg). This is also located under the related links icon at the journal homepage (<http://journals.cambridge.org/ipg>).

Results: This section may contain subheadings. Authors should avoid mixing discussion with the results. Sample sizes should be delineated clearly for all analyses. Some indicator of variability or sampling error should be incorporated into the reporting of statistical results (e.g. standard deviation, standard error of the mean). Wherever possible an indicator of effect size (e.g. Cohens d, η^2 , Cramers V, 95% confidence interval) should be reported in addition to p values. If multiple univariate statistical tests are used p values should be adjusted for multiple comparisons or alternatively a multivariate test should be used. Obtained statistical values for tests should be reported with degrees of freedom (e.g. t, F, χ^2).

Discussion: Interpretation of the results with respect to the hypothesis(es) and their significance to the field should be discussed here. Results should be interpreted in the light of the size of the effect found and the power of the study to detect differences. Any methodological weaknesses of the study should be outlined, including limitations imposed by sample size. Careful consideration of the conclusion(s) for accuracy and alternative interpretation, and possible conflicts or resolution of conflicts in the field is encouraged. Limited speculation and directions for future research can be included.

Conflict of interest declaration: **This section must be completed.** This should follow the discussion and precede the references. Where there is no conflict of interest perceived to be present the heading **Conflict of Interest** should be included with the single word "none" underneath it. For full details see below.

Description of authors' roles: This section must be completed if the paper has 2 or more authors. It should contain a very brief description of the contribution of each author to the research. Their roles in formulating the research question(s), designing the study, carrying it out, analysing the data and writing the article should be made plain. For example: H. Crun designed the study, supervised the data collection and wrote the paper. M. Bannister collected the data and assisted with writing the article. N. Seagoon was responsible for the statistical design of the study and for carrying out the statistical analysis.

Acknowledgements: Any acknowledgements other than conflict of interest declarations in regard to sponsorship should be listed briefly here.

References: No more than 30 articles that have been published or are in press should be cited. If authors believe that more than 30 references are essential this must be justified in the cover letter. Unpublished data, personal communications, and manuscripts submitted for publication should be cited in the text and the supporting material submitted with the manuscript. *International Psychogeriatrics* uses the Harvard referencing system. Within the text of each paper journal articles should be cited in the style (Smith and Jones, 1999). Where an article quoted in the body of the text has more than two authors the term "*et al.*" should be employed, i.e., (Smith *et al.*, 1999). Text citations of multiple articles should be separated by semicolons, i.e., (Smith and Jones, 1999; Smith *et al.*, 1999). At the end of each paper, all cited references should be listed alphabetically in the style indicated below. If the Digital Object Identifier (doi) is known, it should be added to the reference.

For a journal article: Smith, J., Jones, W. I. and Doe, J. T. (1996). Psychogeriatrics for pleasure and profit: an expanding field. *International Journal of Unreproducible Results*, 3, 240–242. doi:12.3456/S123456789.

For a book: Smith, J.A., Brown, P.Q., Jones, H.A. and Robinson, D.V. (2001). *Acute Confusional States*. New York: Cambridge University Press.

For a book chapter: Park, K., Tiger, B. and Runn, F. (1999). Psychogeriatrics in context. In G. Verdi and A. Boito, (Eds.) *New Medical Specialties* (pp. 240–260) Cambridge: Cambridge University Press.

Where an article or book chapter has more than six authors only the first author's name should be given followed by the words "*et al.*".

For further examples of reference style see papers in recent issues of *International Psychogeriatrics*.

Figures/Tables: The manuscript should contain no more than five figures or tables. The copies submitted with the manuscript must be of sufficient quality to enable reviewers to evaluate the data. The journal has a small budget to permit some colour to be printed in some issues but authors wishing to publish figures requiring colour to communicate the data *may* be required to pay some or all the additional cost.

Figure/Table legends: Each caption should begin with a brief description of the conclusion or observation provided in the figure. These should be submitted as a separate section after the References.

Supplementary material: More detail about the submission of supplementary material is available below – see "Supplementary Material for online only publication" and "Instructions for contributors – Supplementary Material" in subsequent pages of this document.

Word limits: At present *International Psychogeriatrics* does not have a fixed word limit for articles, but because of limited space, short articles have a higher chance of acceptance than longer ones of an equivalent standard.

Conflict of interest

Conflict of interest occurs when authors have interests that **might** influence their judgement inappropriately, regardless of whether that judgement is influenced inappropriately or not. *International Psychogeriatrics* aims to conform to the policies of the World Association of Medical Editors in regard to conflict of interest. For full details please see the website <http://www.wame.org/wamestmt.htm#fundres>. To this end all authors must disclose potential conflicts of interest so that others may be aware of their possible effects. Specifically, under the heading conflict of interest, all articles must detail:

The source(s) of financial support for the research (if none, write "none").

A description of any sponsor's role(s) in the research (e.g., formulation of research question(s), choice of study design, data collection, data analysis and decision to publish).

Information about any financial relationship between any author and any organization with a vested interest in the conduct and reporting of the study. For example, in a study on the effects of a drug made by *Bigpharma* which directly competes with another drug made by *Megadrug* a declaration might say "Jane Smith has received research support and speaker's honoraria from *Bigpharma* and has received financial assistance from *Megadrug* to enable her attend conferences."

Reviews of the Literature

International Psychogeriatrics will publish at least 1 literature review in each issue. Authors intending to submit a literature review should check recent issues of *International Psychogeriatrics* to ensure that no review of the topic they propose to discuss has been published in the journal in recent times. Review articles may have up to 50 relevant references. Authors contemplating the submission of a literature review article are welcome to contact the editor to discuss the appropriateness of the topic prior to submission (ipaj-ed@unimelb.edu.au). Literature reviews should have an abstract.

"For Debate" Articles

From time to time *International Psychogeriatrics* will publish "For debate" articles on topics of a controversial nature. "For debate" articles will be commissioned by the editor, but readers are welcome to suggest possible topics for debate by contacting the editor at ipaj-ed@unimelb.edu.au. To view recently published debates see journal issues 19(6), 20(2), and 21(2).

Case Reports

Case reports will be accepted for review and considered for publication. They should be of 1200 words or less and should have no more than 10 references. An unstructured abstract of 100 words or less is required. When submitting case reports authors **must** enclose a **letter of consent to publication** from each of the patient(s) described or, if the patient(s) is/are deceased or not competent to consent the authors must indicate that they have obtained such consent from the patient's legal guardian(s). These letters will be kept confidential.

Study protocol articles

Any author contemplating submission of a protocol only paper is advised to contact the editor of IPG via ipaj-ed@unimelb.edu.au to discuss the paper's suitability for submission prior to submitting it.

Qualitative research articles

Authors of qualitative research articles are advised to contact the editor of IPG via ipaj-ed@unimelb.edu.au to discuss the paper's suitability for the journal before submitting online.

Letters to the Editor

Reader's letters will be considered for publication. Letters should be no longer than 1,000 words and should have no more than 5 references. No abstract is required. Usually tables will not be published in the Letters section of the journal, but may be accepted for online publication as supplementary material at the journal website.

Supplementary Material for online only publication

International Psychogeriatrics has the facility to publish unedited figures, tables, appendices and other material which is not suitable for inclusion in papers published in the paper copy of the

journal as supplementary online material attached to the electronic version of individual papers at <http://journals.cambridge.org/ipg>. This renders such supplementary material accessible without clogging the journal with materials that will be of interest to only a small minority of readers. If submitting such supplementary material please follow the instructions below. If referring to supplementary material in a paper the following form of words should be used “see table S1/figure S1/appendix A1 published as supplementary material online attached to the electronic version of this paper at <http://journals.cambridge.org/ipg>”.

Instructions for contributors – Supplementary Material

There will normally be one of the following reasons for you to be supplying supplementary material to accompany the online version of your article:

1. You wish to link to additional information which due to its nature does not lend itself to print media (examples- full data sets, movie or sounds files etc...)
2. The Editor of the Journal has requested that you extract certain information from the original article in order to allow for space constraints of the print version.
3. You have requested additional material to be available to accompany an article that does not normally allow such material to be included (example – tables to accompany a correspondence article).
N.B. Please note that no copyediting or quality assurance measures will be undertaken on supplementary material (other than to ensure that the file is intact). The authors therefore warrant that the supplementary material that they submit is in a suitable format for publication in this manner. The material shall be published online in exactly the form that it is supplied.

Submission

Please follow the following instructions to supply supplementary material to accompany the online version of your article:

1. Each supplementary file must be supplied as a separate file. Do not supply this material as part of the file destined for publication in the print journal.
2. Each supplementary file must have a clear title (for example, Supplementary Figure 1).
3. Provide a text summary for each file of no more than 50 words. The summary should describe the contents of the file. Descriptions of individual figures or tables should be provided if these items are submitted as separate files. If a group of figures is submitted together in one file, the description should indicate how many figures are contained within the file and provide a general description of what the figures collectively show.
4. The file type and file size in parentheses.
5. Ensure that each piece of supplementary material is clearly referred to at least once in the print version of the paper at an appropriate point in the text, and is also listed at the end of the paper before the reference section.

Format and file size

- File sizes should be as small as possible in order to ensure that users can download them quickly.
- Images should be a maximum size of 640 x 480 pixels at a resolution of 72 pixels per inch.
- Authors should limit the number of files to under ten, with a total size not normally exceeding 3 MB. Sound/movie files may be up to 10 MB per file; colour PDFs/PowerPoint may be up to 5 MB per file; all other general file types may be up to 2 MB per file but most files should be much smaller.

- We accept files in any of the following formats (if in doubt please enquire first):

MS Word document (.doc), Adobe Acrobat (.pdf), Plain ASCII text (.txt), Rich Text Format (.rtf), WordPerfect document (.wpd), HTML document (.htm), MS Excel spreadsheet (.xls), GIF image (.gif), JPEG image (.jpg), TIFF image (.tif), MS PowerPoint slide (.ppt), QuickTime movie (.mov), Audio file (.wav), Audio file (.mp3), MPEG/MPG animation (.mpg)

If your file sizes exceed these limits or if you cannot submit in these formats, please seek advice from the editor handling your manuscript.

Supply of author-generated artwork

Monochrome line subject illustrations supplied as hard copy only

These should have the author's name and figure number clearly marked on the back of each piece of artwork. The figures will be scanned at 1200 dpi and compressed using LZW. The scanning process can result in problems with some fine ornaments and with any grey tints used (e.g. tints can fill in; a Moiré interference pattern can be produced; or poor quality, patchy tints result). Illustrations of this kind may be acceptable in a desktop publishing format, but they do not proceed satisfactorily through the several stages before printing. Plain black/white is acceptable, but all other shades/tints should be replaced with distinct PostScript fills or custom fills.

Monochrome line subject illustrations supplied in digital form

Macromedia Freehand, Adobe Illustrator and Adobe Photoshop are the preferred graphics packages. Before submitting your artwork, please do the following:

- Where possible, please supply illustrations as TIFF or EPS files (300 dpi). When submitting EPS files you must convert your text within the file to artwork/outlines. If your EPS file contains a scanned image, you must ensure that you supply a full EPS, i.e. binary data. Do not supply PostScript files. PostScript files cannot be included within our integrated page make-up system, or worked on in any way. For best results please save your files as TIFF or EPS files. If files cannot be supplied in this way other formats can be handled (although we do not guarantee to use them).
- Draw or scan line artwork to finished size with appropriate line weights and typefaces.
- Indicate the file format (e.g. TIFF or EPS), the graphics software that you have used in originating the artwork files (e.g. Freehand 7.0, Illustrator 8.0, etc.) and the computer operating system used (e.g. Mac OS 8.6, Windows NT).
- Supply a laser print of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork or EPS files.

Pattern fills and tints

Artwork packages do not always generate pattern fills for output on image/platesetters. Imagesetters will interpret them differently from your Mac or PC and the result often looks pixellated or blocked. Where possible, use PostScript fills, custom fills and conventional tints. PostScript fills frequently do not display well on screen but they do print out correctly. It is best to avoid the use of complex or very detailed tints, patterns and symbols. These seldom reproduce satisfactorily when reduced to fit the page and when used in a caption or legend may be completely illegible when represented on a screen (for example during page make-up, or on the Web) or when output on low-quality CUP artwork instructions.doc 2 laser printers. Supplying as TIFF or EPS files (see above) alleviates this problem.

Please therefore:

- Use only the tints, patterns and symbols shown here.
- Use conventional fills: solids, tints, lines or cross-hatching.
- Use a PostScript fill if possible.

- Do not use a screen value above 133 lpi. Generally, 100 lpi is better (even when scanned at high resolution finer tints do not reproduce satisfactorily when reduced).
- If possible, use just one kind of screen (line angle or dot shape) and one screen value throughout the document.
- Do not use pattern fills from a graphics program, as these are usually bitmap patterns, which do not output adequately to plate/image setters.
- Do not use colour tints, even if the figure is intended for monochrome printing; use black/white/greyscale.
- Do not use .hairline. line widths in graphics packages.

Monochrome halftone subjects

Figures composed of (hard copy) photographs should be unscreened glossy prints presented at publication scale; each component part should be named with a lower-case letter. Photographic artwork is numbered as part of the sequence of figures, not as separate plates.

If supplying these in digital form, your repro house should follow these instructions:

- Scanning: Scan at a resolution that is around twice the intended screen value; for example scan at 300 dpi for 133 or 150 screen.
- Dot range (halftones only): This is the term we use to describe the highlight/white area and shadow/black areas within a printed image. To prevent the heavy or dark areas of your halftones from filling in or the light areas being washed out we specify a dot range that allows for gains or losses during the process to lithographic printing. Pre-set the dot range at 1% highlight to 96% shadow where possible, we will check your files before outputting as a safeguard.
- Data files: Supply data as TIFF files; if you wish to compress them, use lossless compression software such as the LZW compression package.
- Laser proofs: Supply a good quality laser proof of all figures. List the name and version of the artwork package used and the names and libraries of fonts used in the artwork. If we are unable to use your electronic file, we can scan in the laser proof as an alternative until a revised file can be supplied.
- Line & tone combination: Files scanned as line & tone combination should be scanned at a higher resolution than a standard halftone to ensure better type/line quality, for example, 600 dpi.

Colour halftone or line subjects

- Do not submit line subject drawings with coloured tints unless the figure is required as a colour plate; use only black/white/greyscale.
- If supplying colour subjects in digital form, submit as TIFF or EPS files and choose CMYK colour mode when saving your scans. If you supply files as RGB we need to convert them to the CMYK printing process before we can print, this usually results in a slight change of the colour values; therefore all colour correction must be carried out in CMYK mode on your machine.

Checklists

- Always supply a printed directory of file names, laser proofs of all the figures, and a list of fonts/typefaces used in labelling artwork.
- Transfer media
- You can supply artwork files in any of the following media:

Apple Mac/PC:

- disks at 3.5 inch
- 100/250 Mb Floppy ZIP drive
- CD-ROM

Virus check

Before dispatching your disks please run them through a virus checker program. If possible, also check Word and Excel files for viruses.

General notes

Following acceptance of a manuscript the contact author should receive proofs within 1-12 weeks. They also will be required to complete and forward a copyright form and authors' checklist both of which will be forwarded to the corresponding author by email when the article is accepted. There is an approximate 4-9 month delay from acceptance of an article to its publication in *International Psychogeriatrics*, but accepted articles will be e-published ahead of print as *First View* Articles within 6-10 weeks of acceptance provided authors return proofs promptly. E-publication generates a doi number and counts as full publication for citation purposes.

Editorials, "For Debate" articles and book reviews are commissioned by the editor.

Reviewers who reviewed papers in the previous calendar year will be acknowledged in the journal each year. *International Psychogeriatrics* no longer publishes an annual index as modern computerised search techniques have rendered annual hard copy indices obsolete.

Contributors should refer to recent issues of the journal for examples of formatting (abstracts, headings, references, tables, etc.).

Office of the Editor-in-Chief

Professor Nicola Lautenschlager
Professor of Psychiatry of Old Age

Editor-in-Chief, *International Psychogeriatrics*,
Normanby House, St George's Hospital
283 Cotham Rd
Kew, Victoria 3101
Australia
Email: ipaj-ed@unimelb.edu.au
Tel: + 61 3 9816 0418
Fax: + 61 3 9816 0477

For book review submissions:

Professor David Ames
Normanby House
St George's Hospital
283 Cotham Road
Kew, Victoria 3101
Australia
Email: dames@unimelb.edu.au
Tel: +61 419378455
Fax: +61 3 9816 0477

For business matters:

Susan M. Oster
Managing Editor, *International Psychogeriatrics*
International Psychogeriatric Association
550 Frontage Road
Suite 3759
Northfield, IL 60093
USA
Email: ipa@ipa-online.org
Tel: +1 847 501 3310
Fax: +1 847 501 3317
Web: www.ipa-online.org

(Revised 5 Jun 2013)

APPENDIX 2 Author guidelines for journal articles written for submission to: Clinical Psychology and Psychotherapy

Author Guidelines

For additional tools visit [Author Resources](#) - an enhanced suite of online tools for Wiley Online Library journal authors, featuring Article Tracking, E-mail Publication Alerts and Customized Research Tools.

Author Guidelines

MANUSCRIPT SUBMISSION

Clinical Psychology & Psychotherapy operates an online submission and peer review system that allows authors to submit articles online and track their progress via a web interface. Please read the remainder of these instructions to authors and then visit <http://mc.manuscriptcentral.com/cpp> and navigate to the *Clinical Psychology & Psychotherapy* online submission site.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created.

All papers must be submitted via the online system.

File types. Preferred formats for the text and tables of your manuscript are .doc, .docx, .rtf, .ppt, .xls. **LaTeX** files may be submitted provided that an .eps or .pdf file is provided **in addition** to the source files. Figures may be provided in .tiff or .eps format.

NEW MANUSCRIPT

Non-LaTeX users. Upload your manuscript files. At this stage, further source files do not need to be uploaded.

LaTeX users. For reviewing purposes you should upload a single .pdf that you have generated from your source files. You must use the File Designation "Main Document" from the dropdown box.

REVISED MANUSCRIPT

Non-LaTeX users. Editable source files must be uploaded at this stage. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

LaTeX users. When submitting your revision you must still upload a single .pdf that you have generated from your revised source files. You must use the File Designation "Main Document" from the dropdown box. In addition you must upload your TeX source files. For all your source files you must use the File Designation "Supplemental Material not for review". Previous versions of uploaded documents

must be deleted. If your manuscript is accepted for publication we will use the files you upload to typeset your article within a totally digital workflow.

COPYRIGHT AND PERMISSIONS

- **Copyright Transfer Agreement**

If your paper is accepted, the author identified as the formal corresponding author for the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors on the paper.

For authors signing the copyright transfer agreement

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

[CTA Terms and Conditions](#)

For authors choosing OnlineOpen

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

Creative Commons Attribution License OAA

Creative Commons Attribution Non-Commercial License OAA

Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on [Wiley Author Services](#) and visit <http://www.wileyopenaccess.com/details/content/12f25db4c87/Copyright--License.html>.

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with Wellcome Trust and Research Councils UK requirements. For more information on this policy and the Journal's compliant self-archiving policy please visit: <http://www.wiley.com/go/funderstatement>.

- **Permission grants** - if the manuscript contains extracts, including illustrations, from other copyright works (including material from on-line or intranet sources) it is the author's responsibility to obtain written permission from the owners of the publishing rights to reproduce such extracts using the Wiley [Permission Request Form](#).

Submission of a manuscript will be held to imply that it contains original unpublished work and is not being submitted for publication elsewhere at the same time.

Title and Abstract Optimisation Information. As more research is read online, the electronic version of articles becomes ever more important. In a move to improve search engine rankings for individual articles and increase readership and future citations to Clinical Psychology & Psychotherapy at the same time please visit [Optimizing Your Abstract for Search Engines](#) for guidelines on the preparation of keywords and descriptive titles.

Manuscript style. The language of the journal is (British) English. All submissions must have a title, be printed on one side of A4 paper with numbered pages, be double-line spaced and have a 3cm wide margin all around. Illustrations and tables must be printed on separate sheets, and not incorporated into the text.

MANUSCRIPT STYLE

The language of the journal is English. 12-point type in one of the standard fonts: Times, Helvetica, or Courier is preferred. It is not necessary to double-line space your manuscript. Tables must be on separate pages after the reference list, and not be incorporated into the main text. Figures should be uploaded as separate figure files.

- During the submission process you must enter the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including email, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**.
- Enter an **abstract** of up to 250 words for all articles [except book reviews]. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.
- All articles should include a **Key Practitioner Message** — 3-5 bullet points summarizing the relevance of the article to practice.
- Include up to six **keywords** that describe your paper for indexing purposes.

Research Articles: Substantial articles making a significant theoretical or empirical contribution.

Reviews: Articles providing comprehensive reviews or meta-analyses with an emphasis on clinically relevant studies.

Assessments: Articles reporting useful information and data about new or existing measures.

Practitioner Reports: Shorter articles that typically contain interesting clinical material.

Book Reviews: Published on invitation only. Critical summaries of recent books that are of general interest to readers of the journal.

Reference style . The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

A. A typical citation of an entire work consists of the author's name and the year of publication .

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

B. If the author is named in the text, only the year is cited .

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .

Example: In a 1989 article, Gould explains Darwin's most successful. . .

D. Specific citations of pages or chapters follow the year .

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

E. When the reference is to a work by two authors, cite both names each time the reference appears .

Example: Sexual-selection theory often has been used to explore patterns of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others") .

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the

reference is to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

G. When the reference is to a work by a corporate author, use the name of the organization as the author .

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows .

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the [DOI](#) for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

Journal Article

Gardikiotis, A., Martin, R., & Hewstone, M. (2004). The representation of majorities and minorities in the British press: A content analytic approach. *European Journal of Social Psychology*, 34 , 637-646. DOI: 10.1002/ejsp.221

Book

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

Book with More than One Author

Natarajan, R., & Chaturvedi, R. (1983). *Geology of the Indian Ocean*. Hartford, CT: University of Hartford Press.

Hesen, J., Carpenter, K., Moriber, H., & Milsop, A. (1983). *Computers in the business world*. Hartford, CT: Capital Press. and so on.

The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.

Web Document on University Program or Department Web Site

Degelman, D., & Harris, M. L. (2000). *APA style essentials*. Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website: http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796

Stand-alone Web Document (no date)

Nielsen, M. E. (n.d.). *Notable people in psychology of religion*. Retrieved August 3, 2001, from <http://www.psywww.com/psyrelig/psyrelpr.htm>

Journal Article from Database

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence*, 15, 503-522. Retrieved May 20, 2000, from ProQuest database.

Abstract from Secondary Database

Garrity, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology*, 20, 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

Article or Chapter in an Edited Book

Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press.

*The Digital Object Identifier (DOI) is an identification system for intellectual property in the digital environment. Developed by the International DOI Foundation on behalf of the publishing industry, its goals are to provide a framework for managing intellectual content, link customers with publishers, facilitate electronic commerce, and enable automated copyright management.

Illustrations. Upload each figure as a separate file in either .tiff or .eps format, the figure number and the top of the figure indicated. Compound figures e.g. 1a, b, c should be uploaded as one figure. Grey shading and tints are not acceptable.

Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Where a key to symbols is required, please include this in the artwork itself, not in the figure legend. All illustrations must be supplied at the correct resolution:

- Black and white and colour photos - 300 dpi
- Graphs, drawings, etc - 800 dpi preferred; 600 dpi minimum
- Combinations of photos and drawings (black and white and colour) - 500 dpi

The cost of printing **colour** illustrations in the journal will be charged to the author. The cost is approximately £700 per page. If colour illustrations are supplied electronically in either **TIFF** or **EPS** format, they **may** be used in the PDF of the article at no cost to the author, even if this illustration was printed in black and white in the journal. The PDF will appear on the *Wiley Online Library* site.

POST ACCEPTANCE

Further information. For accepted manuscripts the publisher will supply proofs to the corresponding author prior to publication. This stage is to be used only to correct errors that may have been introduced during the production process. Prompt return of the corrected proofs, preferably within two days of receipt, will minimise the risk of the paper being held over to a later issue. Once your article is published online no further amendments can be made. Free access to the final PDF offprint or your article will be available via author services only. Please therefore sign up for author services if you would like to access your article PDF offprint and enjoy the many other benefits the service offers

Author Resources. Manuscript now accepted for publication?

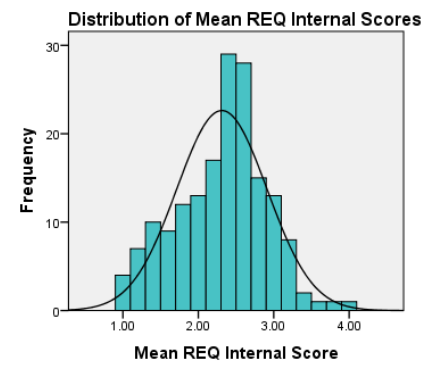
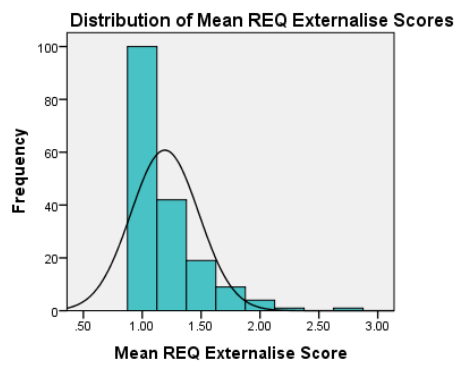
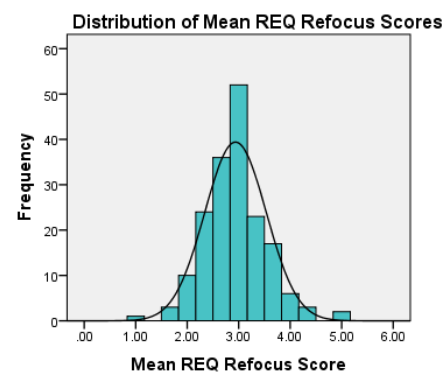
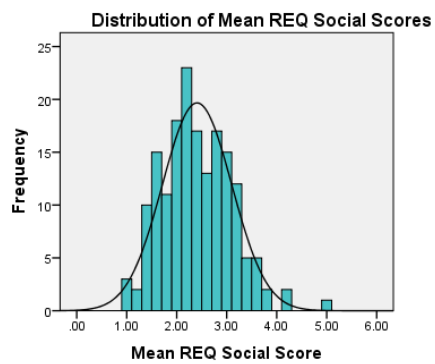
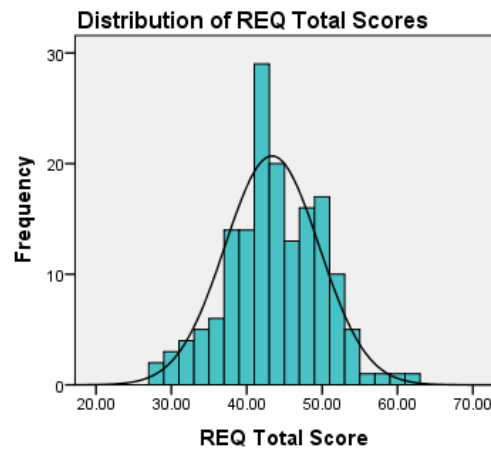
If so, visit our suite of tools and services for [authors](#) and sign up for:

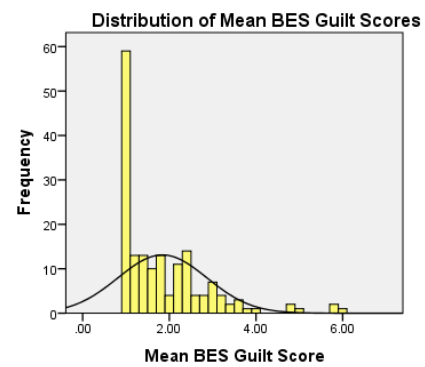
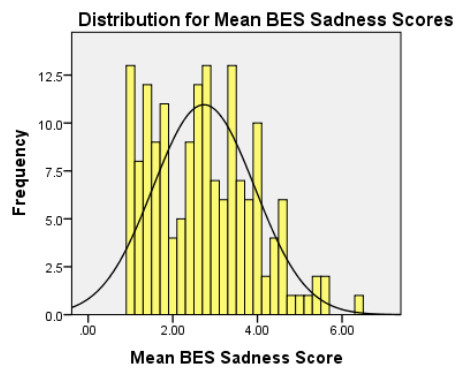
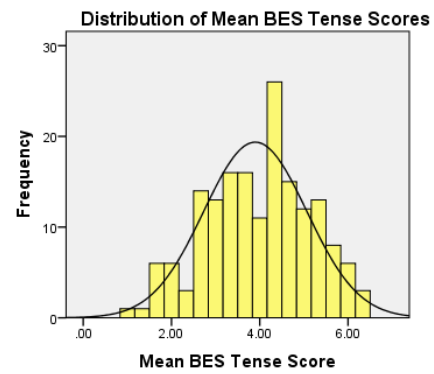
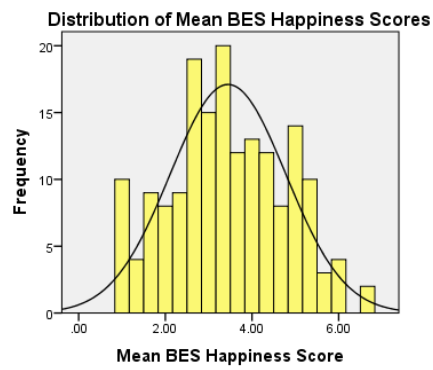
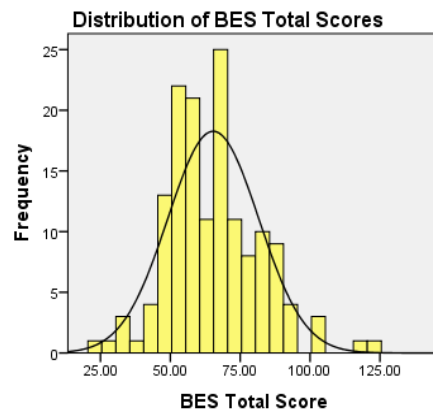
- Article Tracking
- E-mail Publication Alerts
- Personalization Tools

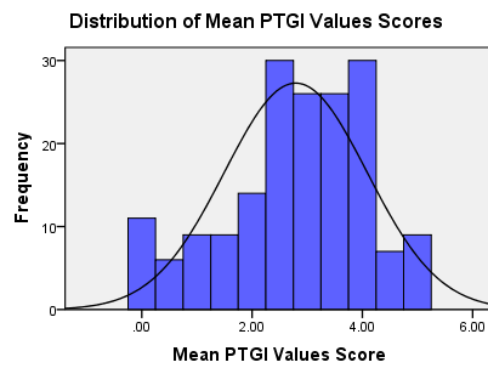
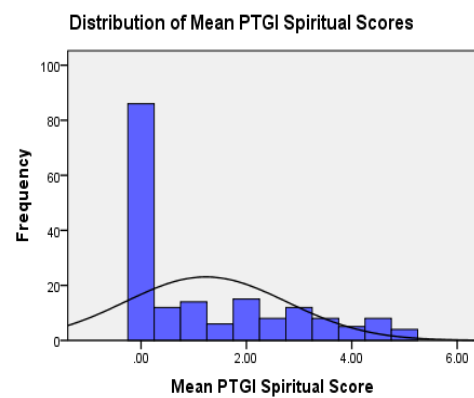
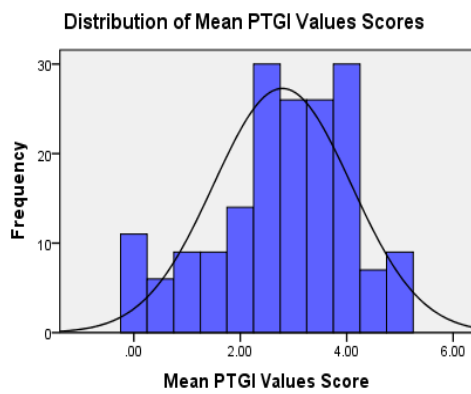
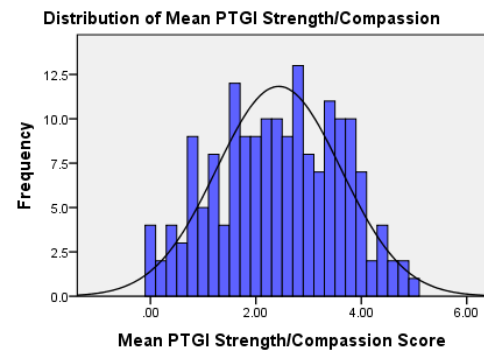
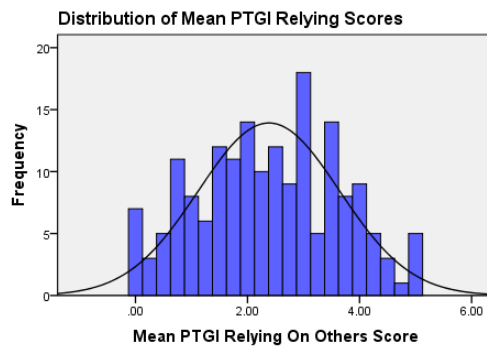
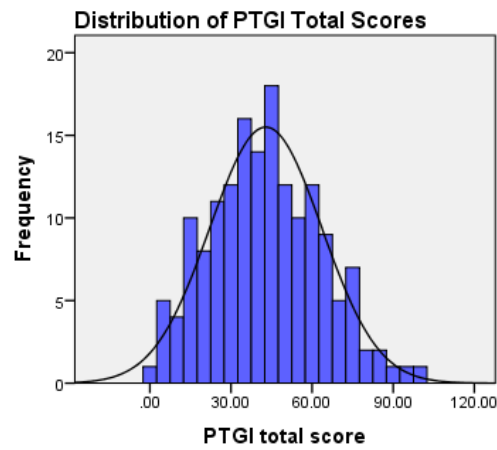
Cite EarlyView articles. To link to an article from the author's homepage, take the DOI (digital object identifier) and append it to "http://dx.doi.org/" as per following example:

DOI 10.1002/hep.20941, becomes http://dx.doi.org/10.1002/hep.20941.

APPENDIX 3 Distribution of scores the BES, REQ and PTGI







Appendix 4 Z Score frequencies for the BES, REQ and PTGI

Zscore: Fear with Frustration (Tension)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	5	2.7	2.9	2.9
	Normal range	165	90.2	97.1	100.0
	Total	170	92.9	100.0	
Missing	System	13	7.1		
Total		183	100.0		

Zscore: BES Sadness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Probable outlier (z score > 2.58)	1	.5	.6	.6
	Potential outlier (z-score > 1.96)	3	1.6	1.8	2.4
	Normal range	161	88.0	97.6	100.0
	Total	165	90.2	100.0	
Missing	System	18	9.8		
Total		183	100.0		

Zscore: BES Guilt

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extreme (z-score > 3.29)	6	3.3	3.6	3.6
	Potential outlier (z-score > 1.96)	3	1.6	1.8	5.3
	Normal range	160	87.4	94.7	100.0
	Total	169	92.3	100.0	
Missing	System	14	7.7		
Total		183	100.0		

Zscore: BES Happiness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	2	1.1	1.2	1.2
	Normal range	170	92.9	98.8	100.0
	Total	172	94.0	100.0	
Missing	System	11	6.0		
Total		183	100.0		

Zscore: REQ Social Support

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extreme (z-score > 3.29)	1	.5	.6	.6
	Probable outlier (z score > 2.58)	2	1.1	1.2	1.8
	Potential outlier (z-score > 1.96)	5	2.7	2.9	4.7
	Normal range	163	89.1	95.3	100.0
	Total	171	93.4	100.0	
Missing	System	12	6.6		
Total		183	100.0		

Zscore: REQ_Internalising

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Probable outlier (z score > 2.58)	1	.5	.6	.6
	Potential outlier (z-score > 1.96)	6	3.3	3.5	4.1
	Normal range	163	89.1	95.9	100.0
	Total	170	92.9	100.0	
Missing	System	13	7.1		
Total		183	100.0		

Zscore: REQ_Externalising

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extreme (z-score > 3.29)	2	1.1	1.1	1.1
	Probable outlier (z score > 2.58)	4	2.2	2.3	3.4
	Normal range	170	92.9	96.6	100.0
	Total	176	96.2	100.0	
Missing	System	7	3.8		
Total		183	100.0		

Zscore: REQ_Refocusing

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extreme (z-score > 3.29)	2	1.1	1.1	1.1
	Probable outlier (z score > 2.58)	1	.5	.6	1.7
	Potential outlier (z-score > 1.96)	6	3.3	3.4	5.1
	Normal range	168	91.8	94.9	100.0
	Total	177	96.7	100.0	
Missing	System	6	3.3		
Total		183	100.0		

Zscore PTGI_Strength/compassion

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	7	3.8	4.0	4.0
	Normal range	168	91.8	96.0	100.0
	Total	175	95.6	100.0	
Missing	System	8	4.4		
Total		183	100.0		

Zscore: PTGI_Relying on others

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	5	2.7	2.8	2.8
	Normal range	171	93.4	97.2	100.0
	Total	176	96.2	100.0	
Missing	System	7	3.8		
Total		183	100.0		

Zscore: PTGI_New Possibilities

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extreme (z-score > 3.29)	1	.5	.6	.6
	Probable outlier (z score > 2.58)	4	2.2	2.3	2.9
	Potential outlier (z-score > 1.96)	4	2.2	2.3	5.1
	Normal range	166	90.7	94.9	100.0
	Total	175	95.6	100.0	
Missing	System	8	4.4		
Total		183	100.0		

Zscore: PTGI_Values

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	11	6.0	6.2	6.2
	Normal range	166	90.7	93.8	100.0
	Total	177	96.7	100.0	
Missing	System	6	3.3		
Total		183	100.0		

Zscore: PTGI_Spiritual

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Potential outlier (z-score > 1.96)	12	6.6	6.7	6.7
	Normal range	166	90.7	93.3	100.0
	Total	178	97.3	100.0	
Missing	System	5	2.7		
Total		183	100.0		

APPENDIX 5 IRAS ETHICAL APPROVAL

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558474
Facsimile: 01224 558609
Email: nosres@nhs.net



21 June 2012

Ms Roisin Ash
Trainee Clinical Psychologist
NHS Grampian
Department of Clinical Psychology
Older Adults
Royal Cornhill Hospital
Cornhill Road
ABERDEEN
AB252ZH

Dear Ms Ash

Study title: **The personal experience of caring for a spouse or partner with dementia**
REC reference: **12/NS/0071**

The Proportionate Review Sub-committee of the NRES Committees - North of Scotland (1) reviewed the above application by correspondence.

Ethical opinion

On behalf of the Committee, the Proportionate Review Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Additional Conditions to be Met

- The Proportionate Review Sub-Committee felt that some of the dementia sufferers may have died and ask that you acknowledge this possibility in the Participant Information Sheet and Letter of Invitation. This could be done by inserting a sentence to the effect that '...we recognise your spouse or partner may have died but we would still want you to take part in the study'.
- The Proportionate Review Sub-Committee wondered whether participants were aware that when they agreed to be on the list, that they would be approached by Postgraduate Researchers. Please comment.
- The Proportionate Review Sub-Committee felt that the Letter of Invitation should come from the Scottish Dementia Clinical Research Network as they are the primary contact for potential participants.

Participant Information Sheet

- Under the heading 'Why have I been chosen?', the Proportionate Review Sub-Committee ask that you remove 'alongside other spousal/partner carers in Scotland, to participate in this research' and replace with 'as you have previously consented to being contacted for future research by the Scottish Dementia Clinical Network'.
- Under the heading 'Do I have to take part?', final sentence, please remove 'Should you wish to withdraw, please return the questionnaires for disposal' as the Proportionate Review Sub-Committee did not feel that the participants should be required to return the questionnaire.
- Under the heading 'What happens if I choose to take part?' final sentence, please remove 'gender' and replace with 'sex'. This will also need to be changed in Q20 of the Carer Questionnaire.
- Under the heading 'Who has reviewed the study', please insert 'The North of Scotland Research Ethics Committee has reviewed this study'.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV: Roisin Ash		24 May 2012
Letter of invitation to participant	2 April 2012	30 April 2012
Supervisor's CV: Ken Laidlaw		13 May 2012
Participant Information Sheet	2 April 2012	30 April 2012
Protocol	2 April 2012	30 April 2012
The Basic Emotions Scale Short Questionnaire	2 April 2012	30 April 2012
Regulation of Emotion Questionnaire	2 April 2012	30 April 2012
Post Traumatic Growth Inventory	2 April 2012	30 April 2012
Carer Questionnaire	2 April 2012	30 April 2012
REC application	108924/332601/1/909	12 June 2012*
Referees or other scientific critique report		26 July 2011

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review.

12/NS/0071	Please quote this number on all correspondence
-------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely

Carol Irvine

PP **Professor Siladitya Bhattacharya**
Chair

Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers" SL-AR2

Copy to: Ms Marianne Laird
Dr Susan Ridge, NHS Grampian

APPENDIX 6

SURVEY COVER LETTER



Dear carer,

Your name and contact details have been provided to us by the Scottish Dementia Clinical Research Network (SDCRN) as you have registered interest in research participation through the Scottish Dementia Research Interest Register.

As part of my Clinical Psychology training, I wish to learn about the experience of dementia care. I am keen to learn from people with experience, past and present, of caring for a spouse or partner with dementia. This includes carers whose spouses/partners: live in the family home, or live outwith the family home, e.g. reside in a care home, or who are deceased. I understand that I have a great deal to learn from varied experiences and I would value the opportunity to learn from your experience of caring past and present.

I recognise that your spouse or partner may now reside outwith your family home or that you may have experienced the death of your spouse or partner but would still like you to take part in the study, if you wish. I would like to invite you to consider participating in my research which uses questionnaires that examine the role of emotion and change through caring. Further information on the questionnaire part of my study is provided on the accompanying Information Sheet for Questionnaire Participants.

Thank you for taking the time to consider your involvement in my research.

Kindest regards,

A handwritten signature in black ink that reads 'Roisin Ash'.

Roisin Ash
Chief Investigator
Clinical Psychology Trainee
NES/University of Edinburgh and NHS Grampian

APPENDIX 7 PARTICIPANT INFORMATION SHEET

Personal experience of caring for a partner with dementia

Version 3 June 2012



INFORMATION SHEET FOR QUESTIONNAIRE RESPONDENTS

1. Study title: **The personal experience of caring for a spouse or partner with dementia.**

2. Invitation to participate

You are being invited to take part in a research study. Before you decide whether you wish to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact me, Roisin Ash, on 07787962177 or by email: roisin.ash@nhs.net

3. What is the purpose of the study?

This study seeks to learn from your experience as a carer which may be in the past or more currently, in particular, to examine the role of emotion and change through caring for a spouse or partner with dementia. We recognise that you may have experienced the loss of your spouse or partner for many reasons including moving to care home and bereavement and would still want you to take part in the study. This research is being conducted by Roisin Ash as part of the doctorate of Clinical Psychology at the University of Edinburgh, under the supervision of Dr Ken Laidlaw. This questionnaire part of this study is completed anonymously using envelope return.

4. Why have I been chosen to participate?

You have been contacted as a carer as you have previously consented to being contacted about future research through the Scottish Dementia Clinical Research Network.

5. Do I have to take part?

No, participation in this study is completely voluntary and you are free to withdraw from this study at any time without explanation or consequence. If you decide to take part, you are free to withdraw from the study at any time and without giving a reason. Any questionnaires that you have completed up to that point will be destroyed and will not be included in the study.

6. What happens if I choose to take part?

If you decide that you wish to take part in my study, please complete the questionnaires when you have the time. This may take up to 30 minutes of your time. We understand that you have other commitments and value learning from your expertise and experience. Questionnaire completion will be taken as evidence that you are consenting to take part in this study. Three questionnaires have been printed on A4 sheets for you to read through and complete in pen at a time and place that is suitable to you:

Post Traumatic Growth Inventory (Tedeschi & Calhoun, 1996; 2004)
 Basic Emotions Scale - short form (Power, 2006; Power & Tarsia, 2007)
 Regulation of Emotions Questionnaire (Phillips & Power, 2007)

The questionnaires require mainly tick-box responses. Additional questions will enable you, for example, to record your sex, time spent in your care role and to write any comments that you wish to do so.

7. Will my taking part in this study be kept confidential?

All data collected by questionnaire will be anonymous and stored confidentially. You are NOT required to provide your name, date of birth or other information that could potentially identify you as a participant. The chief investigator, Roisin Ash, will have access to the data for analysis. All information will be recorded and reported in such a way that responses will not be able to be linked to any individual. The data you provide will be used for the specific research purposes of this study outlined above.

8. How can I take part?

The questionnaire part of this study will run throughout Autumn 2012 – Winter 2013 and if you decide that you would like to participate in this questionnaire study, it would be helpful if you would read and complete the questionnaires when you have the time.

9. How do I return my completed questionnaires?

The return envelopes enable you to return these questionnaires for collection by Roisin Ash at your support group centre. Can I ask that, where possible, you return questionnaires within 3 weeks of receiving them.

10. What will happen to the results of the research study?

Roisin Ash will write up the results of the research in a doctoral thesis which will be held within the University of Edinburgh library.

11. I would like to learn about the findings of the research

It is anticipated that research findings will be available in Winter 2013. If you wish to be provided with a summary of the research findings, please complete the separate opt-in sheet (section A). The opt-in sheet asks for your name and address for sending research findings. This information will be stored securely and separately to your questionnaire responses so that your questionnaire responses remain anonymous. You can also choose whether to be contacted in regards to participating in future research on dementia caring (Section B of the opt-in sheet).

12. Who has reviewed the study?

The North of Scotland Research Ethics committee has reviewed this study.

If you would like to speak with my university supervisor, Dr Ken Laidlaw, please contact: k.laidlaw@ed.ac.uk

If you would like to discuss taking part in my study please contact me, Roisin Ash, either by email: roisin.ash@nhs.net and/or phone: 01224 557497 and/or text on: 07787962177

If you wish to make a complaint about this study, please contact NHS [INSERT RELEVANT COMPLAINTS CONTACT FOR THE NHS REGION IN HERE]

**Thank you for taking the time to read through this information,
it is greatly appreciated.**

APPENDIX 8 Scottish Dementia Clinical Network (SDCRN) Approval

Psychiatry of Old Age
Murray Royal Hospital
Muirhall Road
Perth
PH2 7BH
Telephone Number: 01738 562322
Fax Number: 01738 562481



Roisin Ash
Departmental of Clinical Psychology
Older Adults Services
Block D
Royal Cornhill Hospital
Aberdeen
AB25 2ZH

Our Ref
Enquiries to
Direct Line
E mail

NAN 23
Philip Brown, Administrator
01738 562322
philipbrown1@nhs.net

29th June, 2012

Dear Ms Ash

We have considered your study 'The personal experience of caring for a spouse or partner with dementia' for adoption to the Scottish Dementia Clinical Research Network.

We have pleasure in informing you that the network has approved adoption of your study for the following support:

- Access to carer data

We wish you every success in your project.

We would like to include a brief summary of your study and contact details on our website. Please let me know if this is not acceptable.

Please do not hesitate to contact me for further clarification and assistance when the time arises at emma.law@nhs.net.

Kind regards.

Yours sincerely

EMMA LAW
Manager
Scottish Dementia Clinical Research Network

APPENDIX 9 The Basic Emotions Questionnaire

THE BASIC EMOTIONS SCALE SHORT VERSION

When confronted with some experiences, people may react emotionally. Sometimes some of these emotions prevail over others and linger.

This scale is designed to explore how you have felt since taking on the role of carer for your spouse/partner.

For each emotion please circle **ONE** number only between 1 and 7 to indicate how often you have felt that emotion since you took on the role of carer.

	not at all		some of the time			all of the time	
	1	2	3	4	5	6	7
ANGER	1	2	3	4	5	6	7
DESPAIR	1	2	3	4	5	6	7
SHAME	1	2	3	4	5	6	7
ANXIETY	1	2	3	4	5	6	7
HAPPINESS	1	2	3	4	5	6	7
FRUSTRATION	1	2	3	4	5	6	7
MISERY	1	2	3	4	5	6	7
GUILT	1	2	3	4	5	6	7
NERVOUSNESS	1	2	3	4	5	6	7
JOY	1	2	3	4	5	6	7
IRRITATION	1	2	3	4	5	6	7
GLOOMINESS	1	2	3	4	5	6	7
HUMILIATED	1	2	3	4	5	6	7
TENSE	1	2	3	4	5	6	7
LOVING	1	2	3	4	5	6	7
AGGRESSION	1	2	3	4	5	6	7
MOURNFUL	1	2	3	4	5	6	7
BLAMEWORTHY	1	2	3	4	5	6	7
WORRIED	1	2	3	4	5	6	7
CHEERFUL	1	2	3	4	5	6	7

APPENDIX 10 The Regulation of Emotions Questionnaire (REQ)

Regulation of Emotion Questionnaire

We all experience lots of different feelings or emotions. For example, different things in our lives make us feel happy, sad, angry and so on.

The following questions ask you to think about **how often** you do certain things **in response to your emotions**. You do not have to think about specific emotions but just how often you **generally** do the things listed below.

Please tick the box corresponding to the answer that fits best.
We all respond to our emotions in different ways so there are no right or wrong answers.

In GENERAL how do you respond to your emotions?	<i>Never</i>	<i>Seldom</i>	<i>Often</i>	<i>Very Often</i>	<i>Always</i>
1. I talk to someone about how I feel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I take my feelings out on others verbally (e.g. shouting, arguing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I seek physical contact from friends or family (e.g. a hug, hold hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I review (rethink) my thoughts or beliefs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I harm or punish myself in some way	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I do something energetic (e.g. play sport, go for a walk)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I dwell on my thoughts and feelings (e.g. it goes round and round in my head and I can't stop it)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I ask others for advice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix 10 (continued) The Regulation of Emotions Questionnaire (REQ)

In GENERAL how do you respond to your emotions?	Never	Seldom	Often	Very Often	Always
9. I review (rethink) my goals or plans	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I take my feelings out on others physically (e.g. fighting, lashing out)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I put the situation into perspective	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I concentrate on a pleasant activity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I try to make others feel bad (e.g. being rude, ignoring them)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I think about people better off and make myself feel worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I keep the feeling locked up inside	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I plan what I could do better next time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. I bully other people (e.g. saying nasty things to them, hitting them)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I take my feelings out on objects around me (e.g. deliberately causing damage to my house, or outdoor things)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Things feel unreal (e.g. I feel strange, things around me feel strange, I daydream)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I telephone friends or family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I go out and do something nice (e.g. cinema, shopping, go for a meal, meet people)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix 11 The Post Traumatic Growth Inventory (PTGI)

For each of the following statements please circle the number that best describes any changes in your life as a result of your experience of caring for your spouse/partner.

As a result of caring for my spouse/partner:	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I changed my priorities about what is important in life	0	1	2	3	4	5
I have a greater appreciation for the value of my own life	0	1	2	3	4	5
I developed new interests	0	1	2	3	4	5
I have a greater feeling of self-reliance	0	1	2	3	4	5
I have a better understanding of spiritual matters	0	1	2	3	4	5
I more clearly see that I can count on people in times of trouble	0	1	2	3	4	5
I established a new path for my life	0	1	2	3	4	5
I have a greater sense of closeness with others	0	1	2	3	4	5
I am more willing to express my emotions	0	1	2	3	4	5
I know better that I can handle difficulties	0	1	2	3	4	5

Appendix 11 (continued) The Post Traumatic Growth Inventory (PTGI)

As a result of caring for my spouse/partner:	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
I am able to do better things with my life	0	1	2	3	4	5
I am better able to accept the way things work out	0	1	2	3	4	5
I can better appreciate each day	0	1	2	3	4	5
New opportunities are available which wouldn't have been otherwise	0	1	2	3	4	5
I have more compassion for others	0	1	2	3	4	5
I put more effort into my relationships	0	1	2	3	4	5
I am more likely to try to change things which need changing	0	1	2	3	4	5
I have a stronger religious faith	0	1	2	3	4	5
I discovered that I'm stronger than I thought I was	0	1	2	3	4	5
I learned a great deal about how wonderful people are	0	1	2	3	4	5
I better accept needing others	0	1	2	3	4	5